

# **The influence of Aricept on stress and depression in caregivers**

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## **Declaration**

“This thesis has been composed by myself and the work contained herein is my own”

## **ABSTRACT**

This study investigates the influence of Aricept (Donepezil Hydrochloride) on stress and depression in relatives ( $N=10$ ) who identified themselves as the primary caregivers of a spouse or parent with Alzheimer's Disease. Measures were administered to carers at baseline and 8-12 weeks after their dependant's treatment with Aricept had commenced in order to assess improvement in levels of stress and depression. Data was also collected from a matched sample ( $N=11$ ) to compare levels of stress and depression in carers whose relative was not receiving Aricept. The relationship of patient and carer variables (rated by caregivers) to carer stress and depression was also investigated to see if these improve following pharmacological treatment for dementia. Measures include the Relative's Stress Scale (RSS), the Beck Depression Inventory (BDI), the Behaviour and Mood Disturbance Scale (BMDS) and Gilleard *et al.*'s (1984) Problem Checklist. Quantitative and qualitative results are reported. Results are compared to previous findings and recommendations for future research are discussed.

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## **CHAPTER ONE:**

### **INTRODUCTION**

#### **1.1. Care of older adults with dementia**

Moderate to severe dementia affects about 5 per cent of people over 65 years of age (Livingston, 1994). Alzheimer's disease (AD) is the primary cause of progressive dementia commonly observed in older adults (e.g. Ham, 1997). European prevalence rates are 3.2 per cent among those aged 70-79 years of age and 10.8 per cent among those aged 80-89 years of age (Rocca, Hofman & Brayne, 1991). Epidemiological data from the U.S. indicates that approximately one half of those aged 85 years of age or older have AD (Rice, Fox, Max et al., 1993). Additionally, it is estimated that almost one-quarter of the population of the developed world will be aged 65 or over by the year 2025, compared to only one in seven people today (World Bank, 1993) which suggests that the "care challenge" (Knapp, Wilkinson & Wigglesworth, 1998) will continue to grow. Indeed, it has been proposed that the increase in the number of people with Alzheimer's disease will "outpace the increase in the elderly population as a whole" (Melzer, Ely & Brayne, 1997).

A recent study found that mean disease duration from onset of symptoms to death in Alzheimer's disease was 8.5 years (Jost & Grossberg, 1995). Similarly, the Diagnostic and Statistical Manual of Mental Disorders-4<sup>th</sup> Edition (DSM-IV), 1994 states that the average duration of the illness from onset of symptoms to death is 8-10 years. AD follows an irreversible course which is characterised by progressive decline in cognition, functioning, self-care ability and behaviour which results in the sufferer requiring increasing support until there is usually a need for 24-hour care.

Kavanagh, Schneider, Knapp, Beecham & Netten (1995) found that, in England in 1991, 7 per cent of elderly people with dementia were permanently living in hospitals and another 33 per cent in residential or nursing homes. Similar rates of institutionalisation have been reported for Sweden (Fratiglioni, Forsell, Torres & Windblad, 1994) and Canada (Ostbye & Cross, 1994). However, while the provision of formal care services to support elderly people has been growing in most countries

for some time, the greatest proportion of care still comes from informal sources such as relatives.

In Spain, the proportion of Alzheimer's disease sufferers supported by their family could be as high as 90 per cent (Blanco, 1995), and it is also high in Italy (Cavallo & Fattore, 1994). It is estimated that there are three caregivers carrying some emotional, physical or financial burden for every American with Alzheimer's disease (Bass, Noelker & Rechlin, 1996).

In England, 50 per cent of people with dementia live with another adult in the community (Schneider, Kavanagh, Knapp, Beecham & Netten, 1993) and four out of 10 of these people live with another elderly person, mainly elderly spouses (Melzer, Hopkins, Pencheon, Brayne & Williams, 1994). For those living alone in the UK, care usually comes from woman relatives aged 45-64 (OECD, 1996). It is estimated that in Britain there are approximately six million people caring for others on an informal, unpaid basis in the community; 50 per cent of them have dependants over the age of 75 years (Office of Population Censuses and Surveys, 1989). The estimated cost if the British government were to pay for services provided by informal carers is £34 billion a year (The Scotsman, 1995).

It is clear from the above research that the burden of caring for elderly people with dementia falls mainly on informal carers, usually family and relatives (Ruddle & O'Connor, 1993). Most of this care is provided by one primary caregiver (e.g. Morris, Morris & Britton, 1988a). It is perhaps useful at this point to define informal caregiving as the activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves (Pearlin, Mullan, Semple & Skaff, 1990).

The presence of family caregivers is assumed to prevent institutionalisation and, therefore, the high cost of residential and nursing home care, and hospital inpatient care, of dementia sufferers. However, it has been suggested that caring for a close relative, especially a spouse, who has become demented is one of the most demanding situations that can be encountered (e.g. Rabins, 1984). Baumgarten (1989) argues that several features of dementia can cause particular difficulties for carers, such as its novelty, unpredictability, long duration and ambiguity: factors that have been identified by Lazarus & Folkman (1984) as contributing to the

stressfulness of situations and events. This proposal has been supported by research which indicates that caring for an elderly person with dementia is stressful for caregivers (e.g. Zarit, Todd & Zarit, 1986; see later for further discussion). Thus, the public health impact of dementia extends beyond the patients themselves.

Additionally, there are many indirect costs associated with caregiver inability to cope. For example, in comparison with their non-caregiving contemporaries, caregivers of dementia patients are known to make almost 50 per cent more visits to their General Practitioners and take up to 86 per cent more prescribed medication (e.g. Katon, Kleinman & Rosen, 1982) and stress is a likely mediator of these service contacts. Thus, reducing carer stress is an important issue in health care and a more detailed understanding of the particular aspects of the care situation that are most likely to affect carers would aid the design of interventions to help decrease carer stress and lessen these demands on health care resources (Donaldson, Tarrier & Burns, 1998).

The research that has been generated over the last two decades has indicated that stress associated with caring for a relative with dementia is complex and multifaceted. Aspects of caregiver stress relevant to this study are discussed below.

## **1.2. “Objective” and “subjective” burden**

Attempts to measure and differentiate the dimensions of carer burden have proved difficult because “burden” can be defined in many different ways and, thus, can be measured from different angles (Robinson, 1983). Indeed, throughout the caregiving literature the terms “burden”, “caregiver strain” and “stress” have been used to refer to the same concept. A broad definition of this concept is the consequences for carers of the various practical and emotional demands of caregiving.

Montgomery, Gonyea & Hooyman (1985) made the distinction between caregivers experiencing “objective” and “subjective” burden. The former refers to factors which would be apparent to an observer, such as changes in the dementia sufferer’s behaviour (e.g. Gilleard, 1984), in the carer’s daily routine (e.g. Greene, Smith, Gardiner & Timbury, 1982), physical health (e.g. Proncho & Potashnick, 1989) or financial position (e.g. Gilhooly, 1990), etc. Subjective burden, on the other

hand, is the extent to which carers feel they carry a burden - the emotional reactions to caring (e.g. Morris et al., 1988a). While the same objective situation can be experienced as difficult by one caregiver but not another (e.g. Braithwaite, 1992), a number of studies have demonstrated that high objective burden predicts high levels of stress (e.g. George & Gwynter, 1986; Gilleard, C.J., Belford, Gilleard, E., Whittick & Gledhill, 1984a).

Although some authors have suggested that objective and subjective burden be measured separately (e.g. George, 1994, Zarit (1992) considers that it is difficult to separate out attributions of burden from objective stress as it is possible that carers may find it easier to accept that caring is an exhausting process rather than admit that they themselves are exhausted, possibly because it may be hard for a carer to admit to being stressed. More generally, the terms “burden and “caregiver stress” and “strain” have been used in the caregiving literature to refer to consequences to carers of the various practical and emotional demands of caregiving (Donaldson, Tarrier & Burns, 1997).

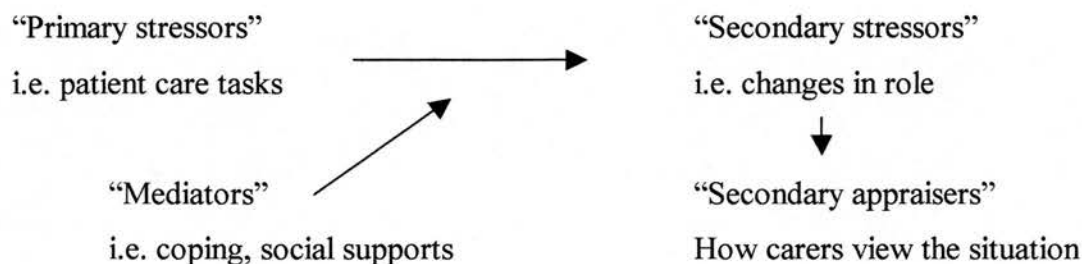
Various authors have attempted to provide conceptual models of Alzheimer’s caregivers’ stress which acknowledge the multi-faceted nature of caregiving and the stress process. Pearlin & colleagues (1990) identified four domains of stress in their study of 555 carers, who were mainly spouses of the patient, in the U.S.A.

- i. Background and context of stress; for example, socioeconomic characteristics, service availability and caregiving history.
- ii. Stressors – primary stressors include the mental and physical dependency of the patient, their needs and behaviour while secondary stressors include role strains, changes in social activities and economic impact. Intrapsychic strains such as competence and self-esteem are also included in this domain.
- iii. Mediators – such as coping skills and social supports.
- iv. Outcomes or manifestations of stress – including emotional distress and changes in the caregiver’s physical health.

Zarit (1992) adapted Pearlin’s processes slightly to form a model of objective and subjective burden of caregiving (see Figure 1). Here the secondary appraisers are

equivalent to subjective burden and the carers' own attributions of their situation. Primary stressors are equivalent to objective burden of caregiving.

**Figure 1.** Model of the Caregiving Process (from Zarit, 1992).



These models illustrate that caregiving stress cannot be viewed as an unitary phenomenon. It is, instead, a mix of circumstances, experiences, responses and resources that vary considerably among caregivers, and that, consequently, vary in their impact on caregivers' health and behaviour (Pearlin et al., 1990). While much research on family care of the dementing elderly was conducted in the 1980s, studies at this time tended to be descriptive as there was little theory or literature to draw on (Gilhooly, Sweeting, Whittick & McKee, 1994). The information gathered at this time initiated the development of conceptual models of caregiver stress (see above) which have, in turn, allowed more recent research to examine specific aspects of caregiving and carer stress. Findings relevant to the present study will be reviewed briefly including psychological distress in carers, determinants of carer stress, characteristics of the patient and the caregiver which contribute to carer stress.

### **1.3. The influence of caring for a relative with dementia on carers**

#### **1.3.1. Psychiatric morbidity**

Most researchers report substantial mental ill-health among dementia carers. Many early studies in this area used the General Health Questionnaire (GHQ) (Goldberg, 1978). General community prevalence rates for GHQ "caseness", or significant emotional distress are around 15-20 per cent (e.g. Goldberg, 1978) whereas Gilleard



and colleagues (1984a) found that the proportion of community caregivers of people with dementia exceeding Goldberg's threshold for caseness fell above 60 per cent. Similarly, Levin, Sinclair & Gorbash (1984) found that just over a third of carers in London scored above the GHQ "caseness" cut-off. Toner (1987) and Whittick (1988) also obtained high GHQ scores among relatives looking after a dementia sufferer. Whittick (1992) found a prevalence rate for GHQ caseness of 31 per cent among her Scottish sample of carers.

In a more recent study, Donaldson, Tarrier & Burns (1998) found that 52 per cent of carers who lived with the person with dementia exceeded the threshold value for "caseness" on the GHQ. Collins & Jones (1997) also found high levels of morbidity in their study of spouse carers demented patients in contact with psychiatric services in Nottingham with 38 per cent of husbands and 65 per cent of wives reaching "caseness".

### **1.3.2. Depression**

Among psychological distress, the most frequent clinical condition examined in caregivers of relatives with dementia is depression. For example, George & Gwyther (1986), using the Affect Balance Scale (Bradburn, 1969), found that caregivers of elderly patients with memory impairments reported higher levels of affect than a demographically comparable community sample.

Estimates for the prevalence of depression in carers of dementia sufferers vary from 14 per cent (Morris et al., 1988) to 77.8 per cent (Harper, Manasse, James & Newton, 1993), with the main body of work reporting prevalence of between 30 per cent and 50 per cent. For example, Zanetti et al. (1998) found a high prevalence of depression in their day hospital sample, with 30 per cent of caregivers exhibiting moderate to severe depressive symptoms. Similar results have been reported in studies conducted in the USA and Canada (Schulz, O'Brien, Bookwala & Fleissner, 1995). A study in England (Coope, Ballard, Saad, Patel, Bentham, Bannister, Graham & Wilcock, 1994) reported a case level of depression in 28 per cent of carers of people with dementia referred to psychiatric services. In Whittick's (1992) Scottish study, scores on the Beck Depression Inventory (BDI; Beck, Ward,



Mendelson, Mock & Erbaugh, 1961), indicated that 43 per cent of caregivers were at least mildly depressed. In a longitudinal study involving 95 spousal caregivers of AD patients, 30-35 per cent were considered depressed at each measurement point (Vitaliano, Russo, Young, Teri & Maiuro, 1991a). This can be compared to a point prevalence rate in adults in community samples of 5-9 per cent for women, 2-3 per cent for men (DSM-IV, 1994). Finally, Saad, Hartman, Ballard, Kurian, Graham & Wilcock (1995) found 29.4 per cent of carers of relatives referred to psychiatric services fulfilled the Research Diagnostic Criteria (RDC; Spitzer, Endicott & Robins, 1978) for depression.

Depression in dementia carers is also more frequent than in control populations. For example, Kiecolt-Glaser, Dura, Speicher, Trask & Glaser. (1991) found that the prevalence of a psychiatric diagnosis of depression was 24.6 per cent among caregivers of relatives with dementia and 0 per cent among volunteer control participants. In a study of adult children caring of a parent with dementia, 24 per cent of carers met DSM-IV (1994) criteria for a depressive disorder compared to 8 per cent of matched controls (Dura, Stukenberg & Kiecolt-Glaser, 1991). Many studies have investigated the relationship between depression and a wide range of caregiver and patient variables (see later).

### **1.3.3. Anxiety**

Relatively few studies have examined anxiety in caregivers. Whittick (1992) and Coope et al. (1995) found that carers' levels of anxiety were not significantly different from those expected in the general population. Similarly, Weiler, Chiriboga & Black (1994) did not find any association between cognitive and daily living deficits in patients and anxiety in carers. In contrast, Gilleard et al. (1982) found a significant correlation between dependency and demand behaviours in patients and anxiety in caregivers. Dura et al. (1991) found that, while the frequency of anxiety disorders did not differ between adult children caring for a parent with dementia and control subjects in the years prior to caregiving, 8 per cent of carers met DSM-IV (1994) criteria for an anxiety disorder during the years they had been providing care compared to 1 per cent of control subjects. Donaldson et al. (1997), in a review of

studies that investigated the impact of patient impairments on caregivers, conclude that too few studies have examined anxiety/stress as an outcome variable to produce conclusive evidence about associations with patient impairments.

#### **1.3.4. Caring for someone with dementia vs. caring for someone with another disorder**

Relatively little research has contrasted caring for someone with dementia to caring for someone with either a physical or other mental disorder. However, McKee, Mutch, Ballinger, Philip, Gilhooly, Whittick & Gordon (1992) found that carers of a dementing old person had higher GHQ scores than a relative looking after a non-dementing well or physically frail elderly person. Baumgarten, Battista, Infante-Rivard, Hanley, Becker & Gauthier (1992) found that family caregivers of older adults with dementia had significantly higher levels of depression and physical ill-health than family members of patients undergoing cataract surgery. Finally, Whittick (1989) found that daughter carers of a parent with dementia had higher GHQ scores than mothers caring for an adult child with a learning disability. In contrast, Draper, Poulos, C.J., Cole, Poulos, R.G., & Ehrlich (1992) found no differences between carers of dementing old people and carers of stroke-impaired elderly people with regard to burden and psychological morbidity.

The paucity of research comparing stress in carers of physically ill and mentally ill relatives may be at least partially explained by the widespread use of scales specifically designed for use with carers of dementia patients (e.g. the Relatives' Stress Scale, Greene, Smith, Gardiner & Timbury, 1982; The Burden Interview, Zarit & Zarit, 1987; The Strain Scale, Gilleard, 1984), rather than more generic measures. Similarly, the use of measures of burden designed for, and validated with, a caregiver population only, prevents direct comparisons with non-caregiving populations and are therefore not useful in determining the degree of stress experienced compared to normal populations. However, Stull, Kosloski & Kercher (1994) concluded from their interviews of 186 carers of dementia sufferers attending psychogeriatric day hospital that burden scales provide valuable information about the caring experience which is not assessed by generic measures

of well-being. This hypothesis is supported by research findings; for example, Eagles, Craig, Rawlinson, Restall, Beattie & Besson (1987), in a community-based study, found that carers of demented and non-demented older adults did not differ with respect to their scores on the General Health Questionnaire but significantly higher scores on the Relatives' Stress Scale (Greene et al., 1982).

#### **1.4. Determinants of carer stress**

The above findings illustrate that caring for a relative with dementia can be stressful for the caregiver. Recent research has examined the determinants of carer stress in dementia in order to understand what specific aspects of dementia, personal characteristics of the caregiver and other variables influence levels of carer stress. These are discussed separately below.

##### **1.4.1. Characteristics of the patient**

###### **1.4.1.1. Behavioural and mood disturbance**

Behavioural disturbance has been found to be a significant factor in carer burden (Absher & Cummings, 1994; Lawlor, 1995). With the exception of Zarit, Reever & Bach-Peterson's (1980) study, all of the research which has assessed some feature of non-cognitive disturbance in dementia sufferers found that these behaviours are closely related to caregiver burden. For example, three studies noted an independent association between aspects of non-cognitive disturbance and GHQ morbidity in carers (Brodaty & Hadzi-Pavlovic, 1990; Draper et al., 1992; LoGuidice, Walrowicz & McKenzie, 1995) while Eagles et al. (1987) found a correlation between carer GHQ scores and a combined measure of disturbed and dependent behaviours.

Coen et al. (1997) found that behavioural disturbance in dementia sufferers, measured by Baumgarten, Becker & Gauthier's (1990) Dementia Behavioural Disturbance Scale, was the strongest predictor of carer burden, measured by the Zarit Burden Interview (Zarit, Orr & Zarit, 1985) both in terms of frequency of disturbance and even more so when tolerability (i.e. how much specific behaviours are a problem for the caregiver) for the various behaviours was taken into account.

Similarly, Donaldson et al. (1998) found that behavioural disturbances (walking, eating, sleeping, aggression, sexual behaviour and emotional lability) in the patient predicted subjective burden in caregivers, measured by the Gilleard Strain Scale (GSS: Gilleard, 1984).

Problematic behaviours associated with dementia can be categorised as acts of either omission or commission. Gilhooly (1994) provided examples of acts of omission as including the inability to prepare a meal, bathe, get dressed, etc, and acts of commission as including smearing faeces, wandering, incontinence. Most research indicated that it is acts of commission which are most difficult and stressful for carers. For example, Rabins, Mace & Lucas (1982) found that physical violence, hitting, accusations and suspiciousness were among the behaviours most frequently cited by carers as problematic while Argyle, Jestice & Brook (1985) found the least well tolerated behavioural problems to be aggression, verbal abuse, wandering, faecal smearing and urination in inappropriate places.

Studies which have measured sub-categories of behavioural disturbances separately have demonstrated differential relationships with burden. For example, Gilleard et al. (1982) report that “demand” type problems contribute most to carer strain and O’Connor et al. (1989) found that physical dependency and disturbed types of behaviours were associated with strain in carers. Greene et al. (1982), using the Relatives’ Stress Scale, found that personal distress in caregivers related to the amount of apathetic and withdrawn behaviour shown by the patient.. Similarly, LoGuidice, Walrowicz & McKenzie’s (1995) study suggested that deficits of behaviour (withdrawal, apathy) are more closely related to carer burden than excesses of behaviour (hoarding, sleep disturbances). Donaldson et al. (1997) proposed that these mood-related deficits may be secondary to depression – in a later study (Donaldson et al., 1998) they found that depression in dependants, assessed by information obtained from carer responses, was the most consistent predictor of psychological morbidity, measured by the GHQ, in carers.

Several studies have examined the relationship between behavioural disturbance in dementia and depression in carers. For example, Baumgarten et al. (1992), Deimling & Bass (1996) and Pruchno & Resch (1989) reported a strong correlation between caregiver depression and aspects of non-cognitive disturbance in

patients. On the other hand, Brodaty & Hadzi-Pavlovic (1990) did not find a significant relationship between these variables in their Australian survey of members of the Alzheimer's Disease and Related Disorders Society.

#### **1.4.1.2. Cognitive features of dementia**

Several studies have investigated the relationship between caregiver stress and cognitive deficits in patients and have failed to make a significant correlation between these two variables (e.g. Greene et al., 1982; Zarit et al., 1980). In a recent study, Coen et al. (1997) found that the degree of the patient's cognitive impairment, assessed using the Cambridge Cognitive Examination (CAMCOG, the cognitive component of the CAMDEX, Roth, Huppert, Tym et al., 1988) and the Mini-Mental State Examination (MMSE (Folstein, Folstein & McHugh, 1975), was not significantly predictive of carer burden, measured by the Zarit Burden Interview (Zarit et al., 1985). Similar results were found by Hadjistavropoulos, Taylor, Tuokko & Beattie (1994) and Mangone, Sanguinetti, Baumann, Gonzalez, Pereyra, Bozzola, Gorelick & Sica (1993). In contrast, LoGuidice et al. (1995) reported a significant positive correlation between cognitive disability and caregiver burden in a mixed-gender sample of carers while Harper & Lund (1990) found that carer-rated memory loss predicted burden in male but not female caregivers.

Where a relationship has been found between caregiver burden and cognitive impairment in the patient, it does not appear to be straightforward. For example, Pruchno & Resch (1989) reported that caregivers whose spouses were "not at all" forgetful experienced significantly less burden than those whose spouses were "sometimes" or "often" forgetful but spouses whose dependants were "sometimes" forgetful experienced significantly more burden than those whose dependants were forgetful "most of the time". Baumgarten et al. (1992) also found a non-linear relationship between cognitive impairments in the patient and caregiver outcomes - carers of patients with intermediate scores on the MMSE experienced significantly higher levels of depression than carers of patients with low or high scores.

Donaldson et al. (1997) suggest that the findings of the two aforementioned studies may be an artefact of the cross-sectional designs employed; that is, group differences other than severity of cognitive problems in patients may have influenced



caregiver scores. However, in a longitudinal study, Reiss, Gold, Gauthier et al. (1994) showed that objective measurements of cognitive impairment were significantly related to caregiver burden at the outset of their study but not at two-year follow-up when cognitive impairment in patients had advanced. An alternative hypothesis is that the non-linear relationship between caregiver burden and cognitive impairment in the patient may be explained by caregiver adaptation. Pruchno & Resch (1989) propose that although caregivers may feel burdened when memory problems initially reach a level that necessitates their assistance (e.g. during the mild to moderate stages of dementia), this burden later abates as supporters adjust to these demands.

#### **1.4.1.3. Functional status**

Functional status, in terms of instrumental activities of daily living and physical self-maintenance functions, were not found to be predictive of carer burden in Coen et al.'s (1997) study. Similar findings have been reported by most other authors (e.g. Greene et al., 1982; LoGuidice et al., 1995; Magone et al., 1993; Zanetti et al., 1998; Zarit et al., 1980). Several studies have explored the relationship between ADL limitations in the patient and caregiver depression. Gilleard et al. (1982) and Brodaty & Hadzi-Pavlovic (1990) measured dependency and disability problems, and Weiler, Chiriboga & Black (1994) rated everyday activities impairments, but no associations with caregiver depression were noted in any of these studies. Baumgarten et al. (1992) also failed to report a significant relationship between measurements of functional impairment and depression in caregivers. However, Deimling & Bass (1986) and Haley et al. (1976) reported significant associations between caregiver depression and ADL limitations and patient deficits in higher-level task performance, respectively, while Grafstrom et al. (1994) found that decreased ADL capacity caused greater burden for the caregiver. Interestingly, Magone et al. (1993) found a significant association between burden and carer ratings of patient activities of daily living (ADL) although there was no association between burden and a direct assessment of patient ADL. The authors suggested that this discrepancy between carer ratings of ADL and direct assessment of ADL could be explained in terms of

burden leading to an underestimation by the carers of the patient's actual functional competence.

These contradictory findings mean that little can be concluded about the impact of ADL limitations on caregiver mood or burden. Analysis of the research methodologies used suggests that these contradictory data may be at least partially attributable to the use of diverse conceptual and operational definitions of ADL limitations (Donaldson et al., 1997) and caregiver adjustment to illness (Pruchno & Resch, 1989).

#### **1.4.2. Characteristics of the caregiver**

##### **1.4.2.1. Gender**

A fairly consistent finding in the literature is that men and women caring for a dementing relative react differently, with men reporting coping rather better than women. For example, George & Gwyther (1986) and Zarit, Todd & Zarit (1986) reported that, among spouse caregivers, wives tended to experience a higher degree of subjective burden or distress while Fitting, Rabins, Luca & Eastham (1986) found that husband and wife caregivers for demented spouses experienced similar degrees of burden but wives reported more depressive symptoms. The presence of psychiatric symptoms was investigated by Pruchno & Resch (1989) using the Hopkins Symptom Checklist, revealing that female carers are more likely than male carers to complain of somatic complaints. In a recent study comparing a sample of wives caring for a spouse with dementia with a matched sample of husband carers, Collins & Jones (1997) found 38 per cent of the husbands and 65 per cent of the wives reached psychiatric caseness on the General Health Questionnaire (Goldberg, 1972). The wives' greater mean GHQ score strongly tended towards significance. Greater subjective burden among women caregivers has also been confirmed in a large population-based survey (Grafstrom et al., 1994).

Gilhooly (1984) argues that the gender differences in coping may be due to three factors; firstly, women show greater emotional over-involvement and are less able than men to step back from their care-giving role. Secondly, women seem less

inclined to leave the house and leave the dementing person on their own so it is harder for them to obtain any respite from caring. Thirdly, she suggests that women may simply be more able to admit to distress than male carers. O'Connor, Pollitt, Roth, Brook & Reiss (1989) suggest that women may find the physical tasks of caring harder than men, while, in addition, male carers are more likely to be taking on a novel role, and as such, may actually find the tasks rewarding or interesting.

This hypothesis is supported by Collin's & Jones (1997) study which found that husbands strongly tended more often to respond positively regarding whether caring gave a "purpose in life that they would otherwise lack" (p. 1171) compared to wives. Harper & Lund (1990) found that female spouses found mood disturbances (e.g. aggression and changes and personality) particularly stressful while, in contrast, symptoms relating to orientation (i.e. requiring a high degree of supervision) were particularly stressful to male spouse carers. Further explanations of possible factors underlying gender differences in caregiver stress are available in Morris, Woods, Davies & Morris (1991) and O'Connor, Pollitt, Roth, Brook & Reiss (1989).

It is of note that most studies report data from more female than male caregivers (e.g. Coen, Swanwick, O'Boyle & Coakley, 1997; Gilleard, Gilleard, Gledhill & Whittick, 1984b). This may be due to two factors; firstly, as women live longer than men more caregivers are likely to be female, and, secondly, adult daughters may assume the role of main caregiver in situations where the male spouse and patient are co-resident.

#### **1.4.2.2. Relationship to the patient**

Among caregiver characteristics, several studies have found that relationship to the patient is an important variable. There is some evidence that carers who are spouses tend to suffer more psychological distress than non-spouses (e.g. Baumgarten et al., 1992, Brodaty & Hadzi-Pavlovic, 1990; George & Gwyther, 1986, but see Donaldson et al., 1998; Dura, Stukenberg & Kiecolt-Glaser, 1991), and wives tend to report higher levels of burden or distress than husbands (e.g. Collins & Jones, 1997; Fitting et al., 1986; George & Gwyther, 1986; Zarit et al., 1986). Zarit et al. (1986) suggest that this difference may be due to men having different strategies for dealing with the dementia sufferer, which enable them to distance themselves from the



everyday problems; for example, they found that husbands were often observed to take a more instrumental approach to daily problems.

Among non-spousal caregivers, daughters are particularly prone to burden and tend to report a high degree of strain (e.g. Coen et al., 1997; Donaldson et al., 1998; Horowitz, 1985). As Gilhooly (1984a) found that the more removed the carer from the patient in terms of blood/role relationship, the better the carer's mental health, daughters may be doubly vulnerable, on the basis of both gender and blood relationship.

#### **1.4.2.3. Perceived competence**

Pearlin et al. (1990) identified low perceived competence, or inability to cope as a potential stressor in their multi-dimensional conceptual model of Alzheimer's caregivers' stress. Although low perceived competence has been identified as a risk factor for depression in caregivers (Coppel, Burton, Becker & Fiore, 1985), little attention has been paid to this variable until recently. However, Haley, Levine, Brown & Bertolucci (1987) found that caregivers' appraisals of themselves as lacking in self-efficacy to manage their dependant's behavioural problems and disability was significantly related to higher levels of caregiver depression. Similarly, Zanetti et al. (1998) found that perceived lower competence in caregiving tasks was significantly associated with depressive symptoms, measured by the Beck Depression Inventory Scale (BDI) (Beck et al., 1961), in spouse caregivers.

Collins & Jones (1997) found that perceived inability to cope, reflected in feeling unable to continue caring for their spouse much longer and being more likely to wish they could leave the care of their spouse to someone else, was higher in wife than husband caregivers. Wives were also more likely to wish that they could cease caregiving but reported more guilt feelings in response to the idea of relinquishing care. The authors suggest that a contrasting subjective obligation to care, due to both husbands and wives strongly tending to view women as better suited to caregiving, and the temptation to relinquish it could be a factor in the higher levels of strain reported by wives.

A recent study found that caregivers who showed a decrease in psychological burden after an educational programme had significantly less knowledge about

Alzheimer's dementia at the beginning of the programme (Magni, Zanetti, Bianchetti, Binetti & Trabucchi [1995]; cited in Zanetti et al., [1998]). Graham, Ballard & Sham (1997) showed that carers of dementia sufferers who had a higher level of knowledge on the subject of dementia had a lower rate of depression and a positive correlation was found between carers' level of knowledge and their feelings of competency. These findings suggest that educational programmes would provide psychological benefits to caregivers with a low level of knowledge about dementia (e.g. Grafstrom & Winblad, 1995).

#### **1.4.2.4. Physical health**

Brodaty & Hadzi-Pavlovic (1990) and Zanetti et al. (1998) revealed a significant relationship between carers' physical functioning and depression, measured by the Zung Depression Scale and the BDI respectively. Deimling & Bass (1986) found that disruptive behaviour and impaired social functioning, but not cognitive impairment, had an impact on caregiver's self-ratings of physical health. However, as only a small number of studies have examined this outcome measure, no decisive determination of the relationship between patient characteristics and the physical health of the caregiver, has been forthcoming.

Zanetti et al. (1998) also found an association between age and the occurrence of depressive symptoms (with older caregivers reporting more depressive symptoms): poor health status is a well-known risk factor for depressive symptoms in older adults (Gurland, Wilder & Berkman, 1988). While poor physical health may arise from the stress of the caregiving role (Draper et al., 1995), having less physical reserve to assist in heavy caregiving tasks (such as help with personal care) may increase burden.

#### **1.4.2.5. Social support**

Research indicates that support from other family members and friends appears to have a moderating influence on burden in the primary caregiver. For example, Zarit et al. (1980) found that more family visits were associated with lower reported burden in the primary caregiver. In contrast, Scott, Roberto & Hutton (1986) found that high burden was reported both by carers who had been rated as not receiving

enough family support, and by those rated as receiving more than enough support. The authors suggest that this occurs because some carers appear to experience such high levels of burden that their families respond by giving them additional support.

Haley et al. (1987) found that caregivers with larger numbers of friends and close relationships and greater subjective satisfaction with their social networks, reported higher self-rated levels of overall life satisfaction and health. Higher levels of social activities with friends, and church attendance, were also significantly correlated with greater life satisfaction. Lower social interaction was also found to be significantly associated with depressive symptoms in Zanetti et al.'s (1998) and Brodaty & Hadzi-Pavlovic's (1990) studies.

As several studies have indicated that ADL problems and supervisory requirements (such as disturbed behaviour) are linked to reductions in caregivers social activities (e.g. Deimling & Bass, 1986; Greene et al., 1982; Pruchno & Resch, 1989), the provision of formal services which allow caregivers to continue with social participation activities (e.g. respite) may be of benefit, in terms of reducing burden, to caregivers. However, it appears that it is not the amount of help given to the primary caregiver that matters, but how satisfied the carer is with the help received (e.g. Coen et al., 1997; Gilhooly, 1984a). Perhaps unsurprisingly in view of the above, caregivers who do not express a need for more social support report higher well-being than those who desire more assistance from friends and family (George & Gwyther, 1986).

#### **1.4.2.6. Identification as primary caregiver**

As mentioned previously, most informal care for disabled older adults is provided by one primary caregiver (e.g. Morris et al., 1988a) and studies have found that self-identification as the primary caregiver is associated with caregiver distress (e.g. Cullen et al., 1997; Grafstrom et al., 1994).

#### **1.4.2.7. Living arrangements**

George & Gwyther (1986) found that caregivers who reside with their dependants reported the highest levels of stress symptoms, lowest levels of mood and life satisfaction, lowest levels of participation in, and satisfaction with, their social

participation. Similarly, Brodaty & Hadzi-Pavlovic (1990) found that carers with a dementing person at home, rather than in a nursing home, were more distressed, as measured by scores on the GHQ. However, recent studies have found that living arrangements are not predictive of caregiver stress; for example, Donaldson et al. (1998) found that carers who lived with the patient or visited him/her on four or more occasions per week did not exhibit significantly different scores on the GHQ or Gilleard's (1984) Strain Scale. It may be that carers who do not reside with the patient experience stress due to worry about leaving the patient unattended for relatively long periods of time while, on the other hand, caregivers who reside with the patient may experience stress due to constant caregiving demands. Additionally, adult children caregivers may find the conflicting demands of their own home life, children, employment and caring for a demented parent stressful. Further research is needed to examine the factors underlying carer stress in relation to co-residence with the patient.

#### **1.4.2.8. Relationship with the patient**

Research has indicated that the quality of the relationship between the caregiver and the dementia sufferer may be an important factor in mediating emotional distress; for example, Gilleard et al. (1984) found that a better past relationship with the patient (rated by the carer) was associated with better mental health in the carer. Morris et al. (1988) found that a low "past" (i.e. pre-caring) level of intimacy was associated with an increased level of both perceived strain and depression in spouse caregivers. They also found that loss of intimacy, caused by the mental deterioration in the dementing partner, correlated with increased levels of depression, but not strain, in the spouse caregiver. Similarly, Brodaty & Hadzi-Pavlovic (1990) found that satisfaction with marriage decreased significantly and carers who were dissatisfied with their current relationship with their spouse were most depressed and reported greater psychological morbidity than those who rated their current relationship as satisfactory.

While no research has been carried out on the influence of past relationship with the dementing parent in adult children, there is evidence that caregivers of frail

elderly relatives who have, and maintain, positive feelings towards their relative report lower levels of perceived strain (Horowitz & Shindelman, 1983).

#### **1.4.2.9. Time demands**

An aspect of disturbed behaviour which has been shown to be associated with depression in caregivers is the time demanded for caring.. For example, Zanetti et al. (1998) measured objective burden by asking caregivers the number of hours daily they dedicated to vigilance (supervision) or assistance (care for activities of daily living) of their spouse. They found that a higher number of hour per day of assistance, but not vigilance, was associated with depressive symptomatology, measured by the Beck Depression Inventory (BDI). Cullen, Grayson & Jorm (1997) also found that levels of caregiver time demands were associated with carer stress, measured by the Relatives' Stress Scale (Greene et al., 1982).

### **1.5. Other variables**

#### **1.5.1. Provision of formal services**

In a review of the literature, Gilhooly (1990) found little evidence that service provision is associated with higher levels of well-being, reduction of burden or a greater willingness to continue providing care among carers of dementing people (see also Zanetti et al., 1998). Indeed, Morris (1986) reported a positive relationship between caregiver strain and formal support while, similarly, Collins & Jones (1997) found a significant positive association between formal supports and GHQ "caseness" in wife caregivers. Morris et al. (1988) suggest that these results may be explained by caregivers who are distressed eliciting relatively high levels of formal support; in other words, increased use of services is a response to higher levels of caregiver distress, rather than a cause of that distress.

Gilhooly (1990) suggests that the fact that services are matched to acts of omission (e.g. providing meals on wheels to those who can no longer cook) rather than acts of commission (e.g. wandering, aggressive behaviour), which appear to be most stressful to carers (e.g. Gilleard et al., 1982; O'Connor et al., 1989), may

explain why there is no straightforward relationship between formal support and burden. However, in many of the studies reviewed by Gilhooly (1990) even when service use was not shown to reduce stress, carers liked services and wanted them.

### **1.5.2. Anti-dementia drugs**

Recent trials of pharmacological therapies indicate that the anti-dementia drugs have an impact on both cognitive and non-cognitive features of mild to moderate Alzheimer's disease. It is of note that pharmacological approaches to Alzheimer's disease (AD) appear to have a symptomatic effect on AD with the disease progressing unabated, as evidenced by withdrawal coinciding with cognitive decrement back to the expected level of deterioration without treatment (e.g. Knapp, Wilkinson & Wigglesworth, 1998). Thus, these drugs do not reverse the disease, nor halt its progression – rather they seem to delay deterioration for approximately 1 year in treated patients (Friedhoff & Rogers, 1997).

#### **1.5.2.1. Anti-dementia drugs and the cognitive features of AD**

Tacrine has been shown to produce significant cognitive improvements in patients with mild to moderate AD compared to placebo based on a four-point improvement on the Alzheimer's Disease Assessment Scale – cognitive subscale score (ADAS-cog) (Rosen, Mohs & Davis, 1984; see also Davis, K.L., Thal, Gamzu, Davis, C.S., Woolson and the Tacrine Collaborative Study Group, 1992). Rogers, Friedhoff and the Donepezil Study Group (1996) found that patients treated with Aricept ([registered trademark of Eisai Co.], donepezil hydrochloride) showed improvement in ADAS-cog and in Mini Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975) scores which was highly significant compared to the placebo group by week 12 of treatment. Similar results were found by Rogers, Farlow, Doody, Mohs, Friedhoff and the Donepezil Study Group (1998) with donepezil - cognitive function, as measured by the ADAS-cog, was significantly improved in the donepezil groups as compared to the placebo group at weeks 12, 18 and 24 but not week 6. Benefits in the donepezil-treated groups were also found using the MMSE and Clinical Dementia Rating – Sum of Boxes (CDR-SB) (Berg, Miller, Baty, Rubin, Morris & Figiel, 1992; Hughes, Berg, Danziger, Coben & Martin, 1982). In



conclusion, the above studies suggest that decline in cognitive function can be slowed down through treatment with donepezil and tacrine.

#### **1.5.2.2. Anti-dementia drugs and the non-cognitive features of AD**

Rogers et al. (1996) examined change from baseline in activities of daily living (ADL) ratings and found significant improvement in patients' mean scores compared to the placebo group 12 weeks into treatment with donepezil. Similar results were found by Rogers et al (1998). The effect of tacrine on non-cognitive behavioural problems in AD was investigated by Raskind, Sadowsky, Sigmund, Beitler & Auster (1997). Compared to the placebo group, the percentage of patients receiving tacrine whose conditions improved or stabilised was significantly greater for three of the ADAS-Noncog items; cooperation in testing, delusions and pacing.

The evidence from the Rogers et al. (1996, 1998) studies and that of Raskind et al. (1997) indicates that the non-cognitive features of AD are positively influenced by cholinergic treatments. These results are particularly relevant in relation to burden in caregivers as many of the stresses of providing care for relatives with AD are related to the non-cognitive features of the disease (e.g. Brodaty & Hadzi-Pavlovic, 1990). Marginal improvements in memory function may offer little to quality of life, whereas reductions in apathy, withdrawal, hallucinations and restlessness may have a major impact on stress in caregivers and families (Knapp et al., 1998). One study, of patients on velnacrine (Clipp & Moore, 1995), has in fact reported a significant reduction in caregiver input time, a response to disturbed behaviour which has been associated with depression in carers (e.g. Zanetti et al., 1998).

Computer database searches and hand searches of the literature indicated that no other studies investigating the influence of pharmacological treatments for AD on caregiver stress have been published at the time of writing.

### **1.6. Summary of the literature**

The care of older adults with dementia falls mainly on informal carers, with most of this care being provided by one primary caregiver. The public health impact of

dementia extends beyond the patients themselves as much research has indicated that caring for an elderly person with dementia is stressful for caregivers in terms of both subjective and objective burden. Studies have reported substantial ill-health among dementia carers in terms of emotional distress, depression, physical ill-health and measures of burden.

Research has indicated that aspects of the patient, characteristics of the caregiver his or herself, and other variables, contribute to carer stress. Stronger and more straightforward correlations exist between the dementia sufferer's behaviour and depressed mood and burden of care in caregivers than their cognitive or functional status. Time demanding for caring, behaviours requiring constant supervision and social disturbances are most problematic for caregivers. Caregiver and relationship characteristics which have been identified as risk factors for adverse caregiver outcomes in terms of wellbeing include a poor previous relationship with the patient, a deteriorating relationship with the patient, carer being female, perceived lower competence in caregiving and ability to cope, and a higher number of hours of assistance required per day.

Regarding other variables, there seems to be a positive relationship between the informal support received by the caregiver and caregiver well-being while receipt of formal support has been associated with both adverse and improved caregiver outcomes. The influence of anti-dementia pharmacological approaches to the treatment of Alzheimer's Disease on caregiver stress has not been investigated.

### **1.7. The pilot study**

Informal feedback from Psychiatrists working with Older Adults in West Fife led the author to believe that carers of spouses with dementia who were receiving donepezil hydrochloride (Aricept), a symptomatic treatment for mild to moderate dementia, were experiencing lower levels of subjective and objective stress and burden than carers whose relatives were not receiving medication aimed at alleviating the symptoms of dementia. Psychiatric casenotes indicated that caregivers often reported that their relative was "more alert", "more their old self" and "calmer" when on Aricept.



A small pilot study involving 14 carers was carried out in August/September 1998 in Fife, Scotland. The study aimed to assess the levels of stress and burden experienced by carers of spouses with Alzheimer's Disease in relation to the prescription of Aricept. A cross-sectional design was employed. All respondents and their spouses were at least 60 years old and lived in Fife. Only participants who cared for their spouse at home were included. Carers were contacted via Carer Support Groups and/or Consultant Psychiatrists in Old Age Psychiatry.

Caregivers of dependants with dementia who were receiving Aricept reported significantly lower levels of burden on the Relatives' Stress Scale (RSS; Greene et al., 1982) and the Care-giving Burden Scale (CGBS; Gerritsen & van der Ende, 1994) than those whose relatives were not receiving antimentia medication.

Analysis of factor scores indicated that caregivers whose spouses received Aricept reported significantly lower levels of burden on the personal distress (subjective burden) and domestic upset (objective burden) factors, but not the negative feelings (subjective burden) factor of the RSS. Mean scores indicated that both groups of carers scored highest on the personal distress factor of the RSS (which includes questions on feeling depressed, needing a break, worry about the care recipient and feeling there will be no end to the problem), with carers in the non-Aricept group reporting higher scores on this factor.

On the Care-giving Burden Scale, analysis of factor scores indicated that carers of spouses suffering from dementia who were receiving Aricept reported significantly fewer personal consequences in relation to caring and evaluated their relationship with their spouse less negatively than those whose spouses were not receiving Aricept. Mean scores indicated that both groups of carers scored highest on the personal consequences factor of the CGBS, which includes questions similar to those found in the personal distress factor of the RSS. As with the RSS, carers in the non-Aricept group reported higher scores on this factor.

The above results indicate that primary caregivers of spouses who are receiving Aricept generally report lower levels of objective and subjective burden than those whose relatives are not receiving Aricept. While a direct measure of depression such as the BDI (Beck et al., 1961) was not administered in this study, scores on the personal consequences factor of the CGBS and the personal distress

factor of the RSS suggests that both groups of carers in this sample may suffer from at least mild levels of depression. Additionally, carers whose relative is receiving Aricept appear to report lower levels of depressive symptoms than those whose relatives are not receiving symptomatic treatment for dementia.

The cross-sectional nature of this pilot study is a limitation in that, for example, the respondents may have been drawn from different populations. The small sample size is also a limitation. However, the results indicate that there is a need for a longitudinal study which examines the caregiving experience before and after the prescription of Aricept to examine the influence of Aricept on stress and burden of care carers. Additionally, data was not collected in the pilot study on patient characteristics which the caregiver may have perceived as improving in relation to medication, such as behaviour, cognitive status and mood; in other words, what changes in the patient may have contributed to the lower levels of stress and burden reported by caregivers.

### **1.8. The present study**

The main objective of this study is to assess improvement in levels of burden of care and depression in relatives who identify themselves as the primary caregiver of a dependant with a diagnosis of mild to moderate Alzheimer's Disease in relation to the prescription of Aricept (donepezil hydrochloride) to their dependent. A second objective is to assess if caregivers' ratings of frequency of behavioural disturbances, and tolerance for behavioural disturbance, and mood characteristics of their dependent improve following the patient's treatment with Aricept.

Thus, following the prescription of Aricept to their dependent:

**Hypothesis 1:** Primary caregivers will report lower levels of stress/burden of care.

**Hypothesis 2:** Primary caregivers will report lower levels of depression.

**Hypothesis 3:** Primary caregivers will report lower levels of apathy/depression in their relative.

**Hypothesis 4:** Primary caregivers will report lower levels of behavioural problems in their relative and (**Hypothesis 5**) how much these are problematic.

A second aim of this study was to compare ratings from self-identified primary caregivers of a related dependant with mild to moderate Alzheimer's Disease receiving Aricept with ratings from those whose relative was not receiving anti-dementia medication (the control group). This allowed comparison of caregivers in the two groups in order to determine if the Aricept group report lower levels of burden of care and depression than the control group (no medication) at follow-up. Ratings of frequency of, and tolerance for, behavioural disturbance in the patient and mood characteristics of the dementia sufferer were also collected in order to allow comparison between groups. Sociodemographic data was collected from both groups at baseline in order to compare group variables including carer gender, carer's relationship to, and with, the patient, living arrangements, duration of dementia, duration of caring and amount of informal support.

It was hypothesised that no differences would be found between groups at baseline; that is, before the prescription of Aricept (donepezil hydrochloride) to dementia sufferers in the experimental group, and that there would be no differences in control group scores over time (i.e. from baseline to follow-up). At follow-up, it was hypothesised that:

**Hypothesis 6:** Primary caregivers whose dependants are receiving Aricept will report lower levels of stress/burden of care than those whose dependant relatives are not receiving anti-dementia medication.

**Hypothesis 7:** Primary caregivers whose dependants are receiving Aricept will report lower levels of depression than those caregivers whose dependant relatives are not receiving anti-dementia medication.

**Hypothesis 8:** Caregivers in the Aricept group will report lower levels of apathy/mood in the dementia sufferer than those whose dependants are not receiving anti-dementia medication.

**Hypothesis 9:** Caregivers in the Aricept group will report lower levels of behavioural problems in their relative and (**Hypothesis 10**) how much these are problematic than those whose dependants are not receiving anti-dementia medication.

## **CHAPTER TWO:**

### **METHODOLOGY**

Approval for this study was sought and obtained from Grampian Research Ethics Committee (approval granted December 1998) and Fife Local Research Ethics Committee (approval granted January 1999). Argyll and Clyde Health Board were also approached informally for ethics permission in January 1999. This application was not pursued further as the proposal would not have been considered until Argyll and Clyde's Local Research Ethics Committee meeting in April 1999 (the suggested deadline for data collection for the Doctorate in Clinical Psychology thesis, University of Edinburgh, was May 1999).

#### **2.1. Participants**

##### **2.1.1. Inclusion criteria for patients**

Participants in this study were carers of a relative who:

- i. had received a diagnosis of probable Alzheimer's Disease (AD) by a Consultant Psychiatrist (Older Adults). These patients were considered to show no evidence of cardiovascular disease, with no clinical or laboratory evidence of a cause other than AD for their dementia [see DSM-IV, 1994 for full diagnostic criteria for AD]
- ii. had scores on the Mini-Mental State Examination (MMSE; Folstein et al., 1975) of 10 to 26 inclusive (patients with scores within this range are considered eligible for treatment with Aricept [e.g. Rogers et al., 1996]), a Clinical Dementia Rating (CDR; Hughes et al., 1982) score of 1 (mild dementia) or 2 (moderate dementia) or were clinically judged as suffering from mild or moderate dementia by a Consultant Psychiatrist (Older Adults)
- iii. were not taking, and had no history of taking, anticholinergic, anticonvulsive, antidepressant or antipsychotic medication, and
- iv. were 60 or more years of age.

### **2.1.2. Inclusion criteria for caregivers**

Participants in this study;

- i. were spouses or adult offspring of the patient
- ii. co-resided with patient or, following Gilleard (1984), provided care at least four separate occasions per week
- iii. self-identified themselves as having been the patient's primary caregiver for at least 6 months.

Carers were excluded if they had cognitive impairment or psychotic illness.

Each patient's cognitive status was measured by Mini Mental Status Examination (MMSE) (Folstein et al., 1975) scores which were obtained from Psychiatry casenotes (the most recent MMSE score obtained from the patient was used as baseline).

### **2.2. Procedure**

Identification of caregivers required two steps. Firstly, suitable patients were identified (see above for criteria) by reference to casenotes and through discussion with Consultant Psychiatrists and Day Hospital Nursing Staff. Identification of spouse or adult child caregivers of suitable elderly patients was obtained in the same way. Caregivers were excluded if the person identified was not the patient's spouse or child.

Potential participants were approached initially by Consultant Psychiatrists or by Day Hospital Nursing Staff who provided them with a brief, verbal outline of the nature of the study. Caregivers who indicated that they would be interested in participating in the study were then sent a letter from the researcher explaining the purpose of the study in more detail (see Appendix A) and then contacted by telephone. If they were willing to participate in the study, an interview was arranged

by telephone and followed up by a letter confirming the appointment. Interviews took place at Whyteman's Brae Hospital, Kirkcaldy, Fife, or the carer's home, depending on which option was most convenient for the caregiver. Two carers declined to take part without giving reasons at this point in the study.

Carers who agreed to participate in the study were interviewed for 1 – 1 ½ hours (baseline). A follow-up interview, dated twelve weeks later, or 12 weeks after the patient was due to commence Aricept, was arranged at the baseline interview. All patients who commenced Aricept did so within four weeks of the baseline interview. Written consent was obtained from participants at the baseline interview (see Appendix B).

Caregivers were also contacted by telephone between the baseline and follow-up interviews to ascertain if they were still willing to be interviewed again. This telephone contact allowed the researcher to check the status of the patient (for example, had they commenced treatment with Aricept, and, if so, on what date had they commenced treatment, had the patient been taken into care) and re-arrange follow-up interviews accordingly. Follow-up interviews also lasted 1 – 1 ½ hours and took place at whichever of the aforementioned locations was convenient for the caregiver.

Baseline data was collected from 24 caregivers. However, follow-up was available from only 21 of participants – in two cases, the patient's condition had deteriorated since the baseline interview and they had been taken into residential care. In these two cases the carers no longer identified themselves as the primary caregiver and, thus, were no longer eligible for inclusion in the study. In one other case the patient was found to have a diagnosis of possible Multi-Infarct Dementia, rather than Alzheimer's Disease, at baseline. Baseline data is not reported for these three carers as follow-up data was not obtained from them. Results are therefore based on data from 21 caregivers. Of these 21 carers, 11 cared for a relative who was not receiving Aricept, 10 for a relative who had commenced Aricept shortly after baseline data had been collected.



### **2.3. Design**

This study compared two groups of self-identified primary caregivers of spouses or parents who had a diagnosis of probable mild or moderate Alzheimer's Disease (AD). A repeated measures design was used – measures were administered to both groups at baseline and at follow-up (12 weeks later). Dependents of caregivers in the experimental group had commenced treatment for AD with Aricept (Donepezil hydrochloride) after baseline whereas dependants of caregivers in the control group had not commenced Aricept or other pharmacological treatment for AD.

The timing of the follow-up interview was based on previous research which found that patients treated with Aricept show significant improvement on measures of cognitive functioning (e.g. Davis et al., 1992; Rogers et al., 1996, 1998) and activities of daily living ratings (Rogers et al., 1996) compared to placebo by week 12 of treatment. All patients who commenced Aricept did so within four weeks of the baseline interview.

A semi-structured interview was conducted with each participant at baseline, and repeated at follow-up. Information was collected on the following: sociodemographic variables, objective burden indicators, the carer's personal resources, primary stressors, stress and depression in carers.

#### **2.3.1. Sociodemographic variables (background and context variables)**

Caregiver's age, sex, relationship with the patient (spouse or adult offspring), whether they were in paid employment or not, and cohabiting/not cohabiting with the patient.



### **2.3.2. Objective burden indicators**

Following Zanetti et al. (1998), caregivers were asked the number of hours daily they dedicated to vigilance (supervision) or assistance (help with ADLs) of their relative.

### **2.3.3. Caregiver's personal resources**

- i. Self-rated health status, using the single item: "How would you rate your overall physical health at the present time?: excellent (score 1), good (2), fair (3), poor (4) (Zanetti et al., 1998). The number of times the carer had visited his/her GP in the last six months (0, 1 or 2, 3 or 4, 5 or more) was recorded as an objective indicator of the carer's physical health. Physical Health. The effect of caregiving on the carer's physical health was assessed by the following question: "Has your physical health been affected by caring for your relative? (Yes/No) (see Section 2.5. and Appendix C).
- ii. Caregiving competence was detected by Pearlin et al.'s (1990) four item scale that essentially asks people to rate the adequacy of their performance as caregivers: "How much do you: (1) believe that you've learned to deal with a very difficult situation; (2) feel that, all in all, you're a good caregiver; (3) feel competent and (4) self-confident about your caregiving?". Response categories were between 1 (not at all) and 4 (considerably) with higher values indicating better perceived competence.
- iii. Information on input from formal services (day hospital, respite, etc) and contact with a Support Group was collected. Carers were also asked if they would like more assistance in caring for their relative from formal services and, if so, what further assistance they would find beneficial.
- iv. Two items were used to evaluate constriction of social activities and longing for these activities (categorised as secondary intrapsychic strains by Pearlin et al., 1990): "Are you able to visit family/friends as often as you would like?; Are you able to engage in hobbies outside the home as often as you would like? (Yes/No).
- v. The role of social support, a potential mediator of caregiving stress (Pearlin et al., 1990) was evaluated by asking carers: "How much do your family help with

caring for your relative? Response categories were between 1 (not at all) and 4 (considerably) with higher values indicating more social support.

Carers were also asked at follow-up, what if anything, had changed about their situation and their relative's functioning since baseline. A semi-structured interview schedule was designed as a guide to obtaining the above social and demographic information (see Appendix C).

#### **2.3.4. Primary stressors**

- i. Caregivers reported on mood problems of the patient by providing answers to the Apathetic-Withdrawn and Mood Disturbance factors of the Behaviour and Mood Disturbance Scale (BMDS; Greene et al., 1982) which provides a frequency count of 21 common problems. Scoring is on a five-point scale (never to always). Scores range from 0 to 105, higher values indicating greater frequency of disturbances (see Section 2.5. and Appendix D).
- ii. Duration of cognitive symptoms. This information was evaluated through asking the primary carers about the time of first appearance of memory deficits and when they first began to provide practical assistance to their relative (see Section 2.5. and Appendix C). These estimates were used to calculate duration of illness and caring respectively (see Donaldson et al., 1998).
- iii. Information on behavioural disturbances was collected by asking caregivers to complete Gilleard et al.'s (1984) Problem Checklist, in which the frequency of 28 problem behaviours (0 – never to 4 – daily or more) and the effects of each (0 – no problem to 2 – major problem) on the carer were recorded (see Section 2.5. and Appendix E).

#### **2.3.5. Outcome variables**

- i. Depression. The presence of depressive symptoms in the caregiver was evaluated with the Beck Depression Inventory (BDI; Beck et al., 1961) where higher values indicate more depressive symptoms (see Section 2.5. and Appendix F).

- ii. Objective and Subjective Burden. (see Section 2.5. and Appendix G). Burden in caregivers was assessed using the Relatives' Stress Scale (RSS; Greene et al., 1982) where higher scores indicate higher levels of stress.

## **2.4. Measures**

### **The Behaviour and Mood Disturbance Scale (Greene et al., 1982)**

The two factors of the Behaviour and Mood Disturbance Scale (BMDS) used in this study are presented in Appendix D. The 31-item BMDS scale was designed to be completed by the main caregiver to assess the degree of behaviour and mood disturbance shown by the patient at home. The original sample consisted of 38 day hospital patients diagnosed by a consultant psychiatrist as suffering from senile dementia. The reliability coefficient for the BMDS (total) was 0.84. Correlations between the sub-scales of the of the BMDS and other measures indicated a degree of construct validity.

Analysis of the scale has provided three factors, two of which refer to overt behaviour, Apathetic-Withdrawn (11 questions) and Active-Disturbed (13 questions), and one of Mood Disturbance (10 questions). Reliability co-efficients for each sub-scale lie between .73 (Mood Disturbance) and .90 (Apathetic-Withdrawn). This scale was chosen as the three sub-scales allow separation of mood and two types of behavioural disturbance. Only the Apathetic-Withdrawn and Mood Disturbance sub-scales were used in this study as active behavioural disturbance and its impact on the caregiver was assessed using Gilleard et al.'s Problem Checklist. The BMDS has been used in published research (e.g. Zanetti et al., 1998)

### **The Relative Stress Scale (RSS; Greene et al., 1982)**

This 15 item self-report scale is presented in Appendix G. The RSS was designed to evaluate burden experienced by careers of relatives suffering from dementing illnesses. It contains questions concerning both subjective and objective dimensions of burden. The original sample consisted of 38 day-hospital patients diagnosed by a consultant psychiatrist as suffering from senile dementia. The reliability coefficient

for the RSS (total) was 0.85 (Pearson correlation co-efficient). Correlations between the sub-scales of the RSS and other measures indicated a degree of construct validity.

Factor analysis of the scale has provided three indices of burden; personal distress (PD) (subjective burden, six items), domestic upset (DU) (objective burden, five items) and negative feelings towards the relative (NF, four items). Reliability co-efficients (Pearson correlation co-efficient) for each sub-scale lie between 0.72 (Personal Distress) and 0.88 (Negative feelings). The scale was chosen as the three sub-scales allow separation of subjective and objective elements of burden. The RSS has been widely used in published research (e.g. Cullen et al., 1997; Draper et al., 1992; Eagles et al., 1987; Vitaliano, Young and Russo, 1991).

#### **Problem Behaviour Checklist (Gilleard et al., 1984)**

This 28-item questionnaire is presented in Appendix E. It was designed to be completed by primary caregivers to assess the frequency of problem behaviours in elderly patients with dementia. The original sample consisted of the primary supporters of 112 psychogeriatric day hospital patients. This scale was chosen as it allows for assessment of problem behaviour and how much these are a problem to the carer; that is, how stressful the carer finds these behaviours. Gilleard's Problem Behaviour Checklist has been used extensively in published research (e.g. Brodaty & Hadzi-Pavlovic, 1990; Collins & Jones, 1997; Cullen et al., 1997; O'Conner et al., 1990).

Note that the above scales (RSS, BMDS, Gilleard's Problem Checklist) are situation-specific and cannot, therefore, be compared with general population norms - scores can only be compared against findings from other studies.

#### **Beck Depression Inventory (Beck et al., 1961)**

The 21-item inventory is presented in Appendix F. It was designed to measure the behavioural manifestations of depression. Each item describes a specific behavioural manifestation of depression (e.g. fatigability, a sense of failure, sleep disturbance, pessimism about the future, etc) and consists of a graded series of four or five self-

evaluative statements ranked to reflect the range of severity of the symptom from neutral to maximal severity. The original sample consisted of 226 psychiatric outpatients, the replication group 183 psychiatric outpatients. Studies of the internal consistency and stability of the instrument indicate a high degree of reliability and comparisons between scores on the inventory and clinical judgements indicated a high degree of validity (Beck et al., 1961).

Although this scale was not designed specifically for use with a caregiving population, it has been widely used to measure depressive symptomatology in caregivers of elderly relatives with dementia (e.g. Dura et al., 1991; Gallagher-Thompson, Brooks, Bliwise, Leader & Yesavage, 1992; Haley et al., 1987; Morrissey, Becker & Rubert, 1990; Whittick, 1992; Zanetti et al., 1998)

## **2.5. Data analysis**

The SPSS Windows package (SPSS/PCT, version 8) was used to test distributional assumptions and perform statistical analyses on the data. Results are reported at the 0.05 level of significance unless otherwise stated.

Independent samples t-tests were used to compare demographic variables involving interval data between the control group (no medication) and the experimental group (Aricept) including age of the carer and the patient, duration of illness and caring, hours spent supervising and assisting the patient per day.

Chi-square was used for comparisons between groups on demographic data in the form of frequencies. This included number of formal supports, place of residence, employment status, attendance at a Carer's Support group, amount of informal support, perceived adequacy of formal and informal supports, ability to visit family and friends or engage in hobbies outside the home, the number of visits carers had made to their General Practitioner in the last six months, the effect of caring on the carer's physical health and their relationship with the patient. However, the expected frequencies in cells of several of the chi-square analyses performed fell below five – the lowest number recommended (Howell, 1982; Robson, 1983). Likelihood ratios

were therefore deemed appropriate for the data as they are considered less affected by small sample sizes than the chi-square (e.g. Howell, 1982).

One-way analysis of variance (ANOVAs) were used to compare group scores on the Relatives' Stress Scale (Greene et al., 1982) and its three factors (Life Upset, Negative Feelings and Domestic Upset), the Behaviour and Mood Disorder Scale (BMDS; Greene et al., 1982) factors (Apathetic-Withdrawn and Mood Disturbance), and Gilleard et al.'s (1984) Problem Checklist - Frequency of behaviours and Tolerance for behaviours). Repeated measures ANOVAs were used for within group comparisons on the aforementioned scales to analyse if group responses changed significantly over time (i.e. baseline to follow-up). As the Levene Test for Equality of Variances (see Kinnear & Gray, 1994, p.92-93) indicated that group variances on Gilleard et al.'s (1984) Problem Checklist – Tolerance for Behaviours and Frequency of Behaviours were heterogeneous, data between-groups was analysed using the Mann-Whitney test and data within- groups was analysed using the Wilcoxon test.

While previous studies of carer stress have used multiple regression analysis to estimate to what extent patient impairment variables (e.g. ADL limitations, depressive features) and background variables reflect the objective circumstances of caring (e.g. living arrangements, amount of support), the small number of subjects in each group in this study limited the use of this method. Regression requires a minimum of 5 times more cases than each independent variable (e.g. Howell, 1982). However, regression analysis was used to compare baseline data from this study to that of previous studies (e.g. Zanetti et al., 1998). Data from the Aricept group and the control group was combined and associations of outcome measures (RSS and BDI) with carer-rated patient variables (frequency of problem behaviour, tolerance for problem behaviours, BMDS Apathy and Mood sub-scales) were assessed separately using linear regression models.



## **CHAPTER THREE:**

### **RESULTS**

#### **3.1. Statistical power**

Cohen (1992) suggests that the number of subjects required for small, medium or large effect sizes (ES) at Power = 0.80 for significance = 0.05 is 393, 64 and 26 respectively for a mean difference or analysis of variance (two groups). Similarly, the number of subjects required for small, medium or large effect sizes (ES) at Power = 0.80 for significance = 0.05 is 785, 87 and 26 respectively for chi-square (1d.f.). While these analyses have been carried out on the data collected in this study, the author is aware that the sample sizes are smaller than those recommended. That is, the number of subjects in each group is lower than that deemed necessary by Cohen (1992) to attain the desired power for the specified significance (0.05) and any hypothesised ES.

A review of the implications of the small sample sizes on the results and the limitations of this study can be found in the discussion.

#### **3.2. Background and demographic information**

The data in Table 1 provide a sociodemographic description of the 21 carers and the 21 AD patients who were involved in the study. Data is reported separately for the experimental group (whose relatives commenced Aricept;  $N = 10$ ) and the control group (no medication;  $N = 11$ ).

##### **3.2.1. Characteristics of carers**

The carer sample in the control group was predominately male (54%). 45 per cent of the carers in this sample were the patient's spouse, 36 per cent the patient's daughter and 18 per cent the patient's son. The sample in the Aricept group was 50 per cent male. 40 per cent of the carers in the Aricept sample were the patient's spouse, 30 per cent were daughters and 30 per cent sons.



**Table 1.** Sociodemographic characteristics of carers and their dependants.

		Group	
		Aricept (N=10)	Control (N=11)
Mean age of carer (SD)		56.4 years (13.11)	62.3 years (14.40)
Mean age of patient (SD)		73.2 years (4.92)	78.2 years (7.56)
Relationship to patient	Wife	2	1
	Husband	2	4
	Daughter	3	4
	Son	3	2
Employed		5 of 10	1 of 11
School-age children		1 of 10	1 of 11
Co-resident with patient		60% (6)	73% (8)
Mean estimated duration of illness (SD)		40.8 months (17.16)	31.0 months (20.48)
Mean length of time of assistance (SD)		28.9 months (17.70)	23.7 months (18.58)
Mean time spent supervising the patient		13.70 (10.93)	20.90 (8.70)
Mean time spent assisting the patient		1.60 (1.58)	2.27 (1.10)
(both hours per day)			

The majority of carers (73%) in the control group lived with the patient; the others (27%) visited their relative with Alzheimer's Disease at least four times per week. Carers who did not co-reside with the patient were all adult daughters. The majority of carers in the experimental group (60%) lived with the patient; the rest of the group visited their relative with Alzheimer's Disease at least four times per week. Carers who did not co-reside with the patient were all adult children (three daughters and one son). Statistical analysis indicated that there was no significant difference between groups on whether carers resided with patients or not (Likelihood Ratio = 0.536, 1 d.f.,  $p = 0.66$ ).

Two carers, one in each group, had school-age children. All but three carers in the sample were married – two sons in the Aricept group and one son in the control group were single and co-resident with the patient. One carer in the no medication group worked outside the home compared to five carers in the Aricept group. Statistical analysis indicated that this difference was significant (Likelihood Ratio = 4.56, 1 d.f.,  $p = 0.43$ ). As may have been expected, carers who worked outside the home were adult children of the patient rather than spouses.

### **3.2.2. Age of carer and patient**

The mean age of carers in the control group was 62.3 years (SD = 14.40; range 39-79) compared with 56.4 years (SD = 13.11; range 39-77) in the Aricept group. The mean age of patients who were not receiving symptomatic treatment for Alzheimer's Disease was 78.2 years (SD = 7.56; range 65-89) in those receiving Aricept it was 73.2 years (SD = 4.92; range 65-79). Independent t-tests indicated that there was no significant difference between groups in terms of the age of the carers ( $t = 0.97$ , 19 d.f.,  $p = 0.34$ ; two-tailed) or the age of the patients ( $t = 1.77$ , 19 d.f.,  $p = 0.09$ ; two-tailed).

### **3.2.3. Duration of illness and caring**

The mean length of time over which carers estimated that their relative had exhibited problems with memory or other signs of dementia was 31 months (SD = 20.48; range 6-60) in the control group and 40.8 months (SD = 17.16; range 24-72) in the Aricept group. The mean length of time over which carers had supported the patient in the control group was 23.73 months (SD = 18.58; range 6-60) and 28.9 months (SD = 17.70; range 7-60) in the Aricept group. Independent t-tests indicated that there was no significant difference between groups on time spent caring ( $t = 0.65$ , 19 d.f.,  $p = 0.52$ ; two-tailed) or duration of symptoms ( $t = 1.18$ , 19 d.f.,  $p = 0.25$ ; two-tailed).

### **3.2.4. Time spent supervising and assisting the patient**

At baseline, the mean length of time carers estimated that they spent supervising their relative was 20.90 hours per day (SD = 8.70; range 2-24 hours) in the control group, 13.70 hours (SD = 10.93; range 2-24) in the Aricept group. The high number of hours obtained for this question may be at least in part explained by frequent responses to the question "How many hours per day do you spent supervising your relative?" being "all the time" (eight respondents) and "24 hours per day" (four respondents). When asked further about these responses, carers tended to explain that they were constantly supervising, or "keeping an eye on", their relative due to worry about accidents occurring or help being required. Examples of such feared accidents were; wandering out of the house unaccompanied, burning food or themselves, leaving fires or gas rings alight and letting strangers into the house. An independent t-test indicated that there was no significant difference between carers whose relatives were receiving Aricept and those whose relatives were not in terms of time spent supervising the patient ( $t = 1.49$ , 19 d.f.,  $p = 0.15$ ; two -tailed).

The average length of time carers estimated that they spent assisting the patient at baseline was 2.27 hours per day (SD = 1.10; range 1-4) in the control group, 1.60 hours per day (SD = 1.58; range 0-4) in the Aricept group. An independent t-test indicated that there was no significant difference between the two groups in terms of time spent assisting the patient ( $t = 0.14$ , 19 d.f.,  $p = 0.27$ ; two-tailed).

### **3.2.5. Formal and family support**

Data pertaining to formal and informal support is reported in Table 2.

Information collected at baseline showed that all patients received input from services other than their General Practitioner. All patients received input from Psychiatry, five patients (50%) in the Aricept group and four (36.4%) controls attended day hospital, four patients (40%) in the Aricept group but no controls had a home carer, one patient (10%) in the control group but none of those who later

received Aricept had been in respite, two (20%) and one (9.1%) respectively had input from a Community Psychiatric Nurse (CPN) and five (50%) of patients in the Aricept group and two (18.2%) controls had a Social Worker. Statistical analysis indicated that groups did not differ significantly in terms of the amount of formal support they reported receiving (Likelihood Ratio = 1.77, 2 d.f.,  $p = 0.41$ ).

Information from subjects indicated that the provision of formal services, particularly those which provided the “respite” time (e.g. Day Hospital) were liked by carers.

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**Table 2.** Formal and informal support received by patients and carers.

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	Group	
	Aricept <i>N</i> (%)	Control <i>N</i> (%)
N of formal supports		
One	3 (30)	1 (9.1)
Two	2 (20)	4 (36.4)
Three or more	5 (50)	6 (54.5)
More formal assistance desired	1 (10)	6 (54.5)
Family help		
“Not at all”	2 (20)	2 (18.2)
“A little”	0 (0)	3 (27.3)
“Sometimes”	2 (20)	0 (0)
“Quite a lot”	4 (40)	2 (18.2)
“Considerably”	2 (20)	4 (36.4)
More assistance from family desired	2 (20)	2 (18)
Attending Support Group	0 (0)	1 (9)

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At baseline, 45.4 per cent of the control group reported that the formal support they received in caring was adequate while 55 per cent stated that they would like more help from formal services in caring for their relative. In contrast, 90 per cent of carers whose relative later commenced Aricept reported that the formal support they

received was adequate. Statistical analysis indicated that this difference was significant (Likelihood Ratio = 5.07, 1 d.f.,  $p = 0.02$ ). Thus, while groups did not differ significantly in the amount of formal support they reported receiving, control subjects wished for more formal support. Day hospital, a home carer and respite were the main types of further formal assistance that carers stated they would find beneficial.

9 per cent and 0 per cent of subjects in the no medication and Aricept groups respectively attended a Carer's Support Group (Likelihood Ratio = 1.34, 1 d.f.,  $p = 0.25$ ; not significant) although most carers (73% and 70% respectively) knew that such groups ran locally. Reasons voiced for not attending a Support Group were being unable to leave the patient alone for more than 1 hour, too many other time demands and lack of transport.

In terms of informal support, 20 per cent of carers in the Aricept groups reported that their family helped with caring for their relative "not at all" compared to 18.2 per cent of carers in the control group. In all other cases, family help with caring ranged from "a little" to "considerably" (see Table 2). Statistical analysis indicated that the differences between groups were not significant (Likelihood Ratio = 8.24, 4 d.f.,  $p = 0.08$ ).

81.8 per cent of carers in the control group and 80 per cent of carers whose relative later received Aricept stated that they were satisfied with the assistance in caring for their relative they received from other family members. There was no significant difference between the responses from the two groups on this item (Likelihood Ratio = 0.01, 1 d.f.,  $p = 0.92$ ).

63 per cent of carers in the control group and 60 per cent of carers in the experimental group reported that they were not able to visit friends and family as often as they would like due to the demands of caregiving. There was no significant difference between the responses from the two groups on this item (Likelihood Ratio = 0.30, 1 d.f.,  $p = 0.86$ ). In contrast, 71 per cent of control subjects and 90 per cent of experimental subjects stated that they were able to engage in hobbies outside the home as often as they would like (Likelihood Ratio = 1.06, 1 d.f.,  $p = 0.83$ ; no significance).

### 3.2.6. Carer's physical health

Data pertaining to the carer's self-rated physical health, number of visits to their General Practitioner and the effect of caring on the carer's physical health are presented in Table 3.

**Table 3.** Carer's physical health: self-ratings, visits to GP and effect of caring on physical health.

	Group	
	Aricept <i>N</i> (%)	Control <i>N</i> (%)
Self-rated health		
Excellent	3 (30)	1 (9.1)
Good	3 (30)	3 (27.3)
Fair	1 (10)	3 (27.3)
Poor	3 (30)	3 (27.3)
Very poor	0 (0)	1 (9.1)
N of G.P visits in last 6 months		
None	3 (30)	1 (9.1)
1 or 2	3 (30)	2 (18.2)
3 or 4	0 (00)	1 (9.1)
5 or more	4 (40)	7 (63.6)
Health affected by caring	3 (30)	5 (45.5)

Chi-square indicated that there was no significant difference between groups in terms of number of visits carers made to their General Practitioner in the previous six months (chi square = 0.53, 1 d.f.,  $p = 0.46$ ; see Table 3 for frequencies). Similarly, there was no significant difference between groups on the question "Has your physical health been affected by caring for your relative?" with 54.6 per cent of controls and 70 per cent of experimental subjects responding negatively (Likelihood Ratio = 0.53, 1 d.f.,  $p = 0.46$ ; see Table 3 for frequencies). There was no significant difference between groups in terms of self-rated health status (Likelihood Ratio = 3.43, 4 d.f.,  $p = 0.49$ ).

### **3.2.7. Relationship with patient**

27.3 per cent of controls and 40 per cent of carers whose relative later commenced treatment with Aricept stated that their relationship with the patient had deteriorated “not at all” since the onset of their illness. 45.5 per cent and 40 per cent respectively stated that their relationship had deteriorated “a little”, 18.2 per cent and 10 per cent respectively that it had deteriorated “moderately, and 9.1 per cent and 10 per cent that it had deteriorated “quite a lot”. Analysis indicated that there was no significant difference between groups in respect of their assessment of the effect of caring on their relationship with the patient (Likelihood Ratio = 3.32, 4 d.f.,  $p = 0.51$ ).

### **3.2.8. Self-ratings of caregiving competence**

The scores obtained from subjects on Pearlin et al.’s (1990) four item rating scale (“How much do you: (1) believe that you’ve learned to deal with a very difficult situation; (2) feel that, all in all, you’re a good caregiver; (3) feel competent and (4) self-confident about your caregiving?”) were collapsed to give one score – caregiving competence. The mean response to this item was 11.30 (SD = 2.71) in the control group and 9.78 (SD = 2.05) in the Aricept group. An independent t-test indicated that there was no significant difference between groups on self-rating of their competence as caregivers ( $t = 1.37$ , 19 d.f.,  $p = 0.19$ ; two-tailed). Given the possible range of scores (0-16) the obtained mean scores indicate that most carers rated their caregiving competence as above average.

### **3.2.9. Summary of background and demographic information**

Statistical analysis found no difference between the two groups on age of carers and patients, duration of symptoms and illness, residential status, time spent supervising and assisting the patient, attendance at a Support Group, amount of and satisfaction with family help with caring, self-rated caregiving competence and physical health, number of G.P. visits in the last six months, ability to visit family/friends and engage



in hobbies outside the home as often as they would like, number of formal supports, effect of caring on relationship with the patient.

Groups differed on only two variables. Subjects in the control group wished more assistance in caring with their relative from formal services than subjects in the Aricept group. Carers in the Aricept group were more likely to work than controls.

### 3.3. Comparisons between groups

Clinical characteristics of the carers and carer reported characteristics of the patients at baseline and follow-up are provided in Table 4.

**Table 4.** Clinical characteristics of the carers and patients at baseline and follow-up.

	Group			
	Aricept (N=10)		Control (N=11)	
	Mean (SD)		Mean (SD)	
	Baseline	Follow-up	Baseline	Follow-up
Relative Stress Scale				
Total	24.00 (11.95)	22.90 (14.43)	28.82 (10.44)	31.73 (15.47)
Life Upset	6.40 (3.89)	6.90 (5.47)	10.00 (4.09)	9.91 (5.15)
Negative Feelings	5.80 (3.49)	5.20 (4.24)	5.73 (3.50)	7.09 (4.76)
Personal Distress	11.80 (5.57)	10.80 (5.63)	13.09 (4.48)	14.55 (6.92)
Behaviour and Mood Disturbance Scale				
Apathy sub-scale	22.90 (7.08)	20.90 (6.08)	30.00 (6.97)	30.91 (5.92)
Mood Sub-scale	19.00 (7.26)	17.80 (7.24)	18.45 (10.13)	19.36 (10.98)
Behaviour Checklist				
Frequency of behaviours	21.10 (8.25)	17.60 (8.98)	27.5 (12.60)	30.91 (14.57)
Tolerance for behaviours	14.44 (7.06)	12.00 (8.37)	18.8 (14.84)	21.60 (18.12)
Beck Depression Inventory (frequency and [percentiles])				
0-9 (no depression)	6 (60.0)	7 (70.0)	6 (54.5)	7 (63.6)
10-18 (mild depression)	3 (30.0)	2 (20.0)	2 (18.2)	1 (9.1)
19-29 (moderate depression)	0 (0.0)	0 (0.0)	2 (18.2)	2 (18.2)
30 or more (severe depression)	1 (10.0)	1 (10.0)	1 (9.1)	1 (9.1)

3.3.1. Baseline

3.3.1.1. Relatives’ Stress Scale

A one-way analysis of variance (ANOVA) showed that there was no significant difference between groups on total scores for the Relatives’ Stress Scale at baseline (RSS;  $F = 0.97$ , d.f. = 1, 19,  $p = 0.34$ ). Analysis of the three sub-scales of the RSS showed that there was no significant difference between groups on responses to the Negative Feelings factor ( $F = 0.002$ , d.f. = 1,19,  $p = 0.96$ ), the Personal Distress factor ( $F = 0.35$ , d.f. = 1,19,  $p = 0.56$ ) or the Life Upset factor ( $F = 4.24$ , d.f. = 1, 19,  $p = 0.05$ ) at baseline. The result obtained for Life Upset indicates that there was a tendency for subjects in the control group to report higher scores on this factor than those in the Aricept group (see Table 4 and Chart 1 for mean scores).

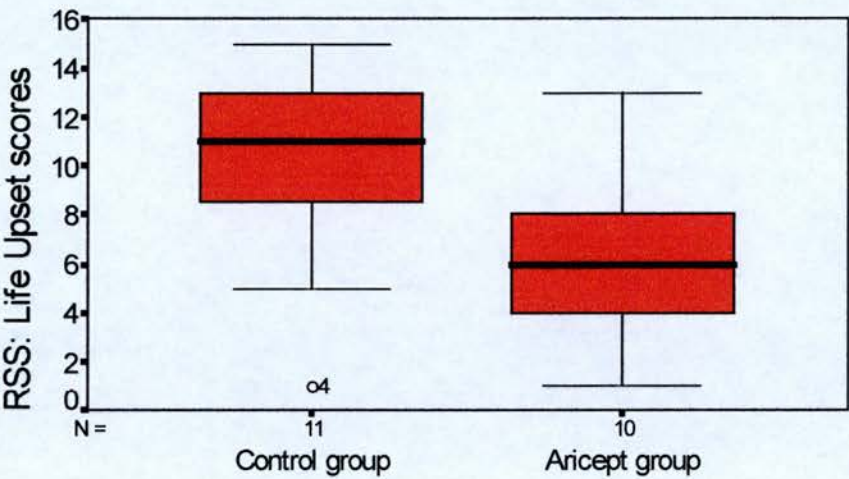


Chart 1. RSS Life Upset scores at baseline

3.3.1.2. Beck Depression Inventory

A chi-square indicated that group responses on the BDI did not differ significantly at baseline (Likelihood Ratio = 2.93, d.f. = 3,  $p = 0.40$ ). The data provided in Table 4 indicate that more than half of the subjects in each group scored in the “not depressed” range of the BDI. 30 per cent of the control group and 18.2 per cent of the Aricept group exhibited mild depressive symptomatology, 0 per cent and 18.2 per

cent respectively moderate symptomatology and 10 per cent and 9.1 per cent severe symptomatology.

**3.3.1.3. Behaviour and Mood Disturbance Scale**

Analysis of the two sub-scales of the BMDS showed that there was no significant difference between groups on the Mood Disturbance factor ( $F = 0.02$ , d.f. = 1,19,  $p = 0.89$ ) while a significant difference was found on the Apathy-Withdrawn factor ( $F = 5.36$ , d.f. = 1, 19,  $p = 0.03$ ). Table 4 and Chart 2 show that the control group reported higher mean scores ( $M = 30.00$ ) on this factor than did carers whose relative later commenced treatment with Aricept ( $M = 22.90$ ).

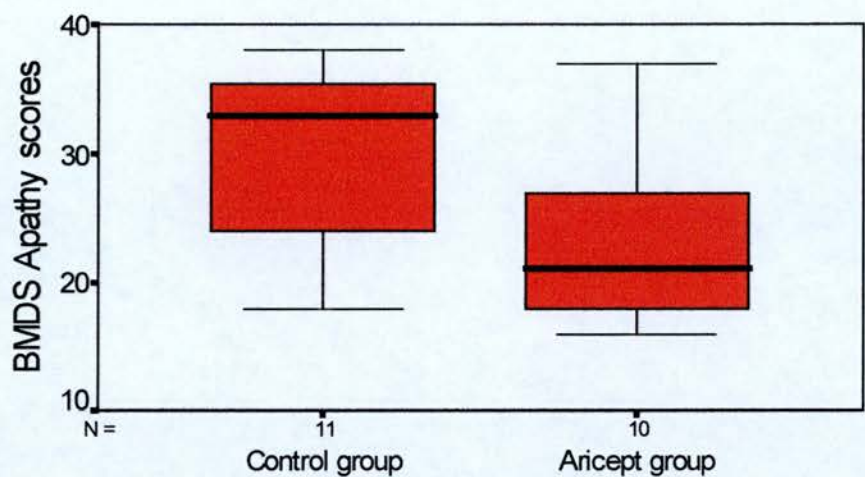


Chart 2. BMDS Apathy scores at baseline

**3.3.1.4. Problem Checklist**

Analysis using nonparametric statistical tests showed that there was no significant difference between groups at baseline on the Problem Checklist – Frequency of Behaviours ( $U = 35.50$ , d.f. = 10, 11,  $p = 0.17$ ; two-tailed; see Chart 3) or the Problem Checklist - Tolerance for Behaviours ( $U = 49.00$ , d.f. = 10, 11,  $p = 0.97$ ; two-tailed; see Chart 4).

The data presented in Table 4, Charts 4 and 5 indicate that carers in the control group reported more problem behaviours in their relative and less tolerance for these behaviours than did carers in the Aricept group although these differences were not significant.



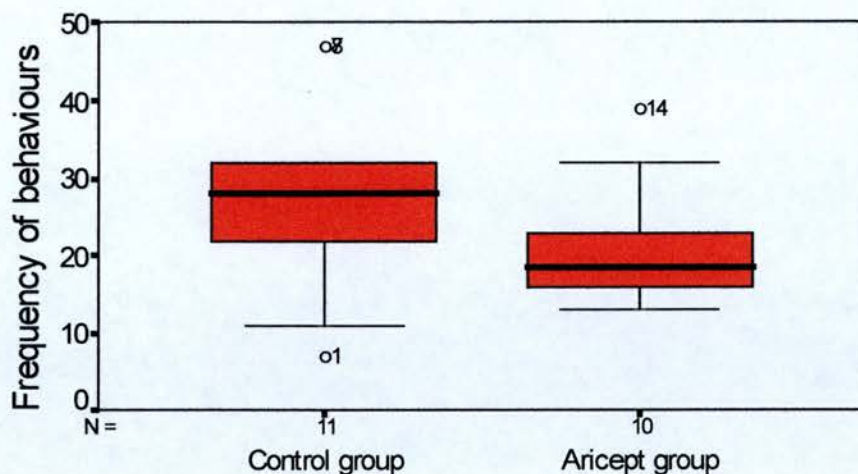


Chart 3. Frequency of problem behaviours (baseline)

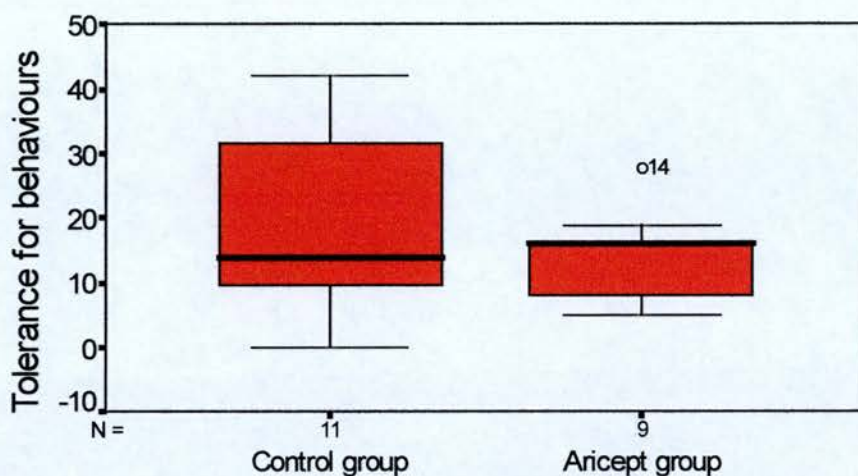


Chart 4. Tolerance for problem behaviours (baseline)

### 3.3.1.5. Summary

Statistical analysis confirmed the hypothesis that no significant differences would be found between groups at baseline, before the prescription of Aricept (donepezil hydrochloride) to dementia sufferers in the experimental group, on scores reported on the BDI, RSS, BMDS Disturbance sub-scale and Problem Behaviour Checklist – Frequency of Behaviours and Tolerance for Behaviours. However, group scores on the BMDS Apathy/Withdrawn sub-scale differed significantly at baseline.

### **3.3.2. Follow-up**

#### **3.3.2.1. Relatives' Stress Scale**

A one-way analysis of variance (ANOVA) showed that there was no significant difference between groups on total scores for the Relatives' Stress Scale at follow-up (RSS;  $F = 1.82$ , d.f. = 1, 19,  $p = 0.19$ ). Analysis of the three sub-scales of the RSS showed that there was no significant difference between groups at the 0.05 level of significance on responses to the Negative Feelings factor ( $F = 0.92$ , d.f. = 1, 19,  $p = 0.35$ ), the Personal Distress factor ( $F = 1.83$ , d.f. = 1, 19,  $p = 0.19$ ) or the Life Upset factor ( $F = 1.69$ , d.f. = 1, 19,  $p = 0.21$ ). The result obtained for Life Upset indicates that the tendency for subjects in the control group to report higher scores on this factor than those in the Aricept group at baseline had decreased by follow-up.

#### **3.3.2.2. Beck Depression Inventory**

A chi-square indicated that group responses on the BDI did not differ significantly at follow-up (Likelihood Ratio = 3.07, d.f. = 3,  $p = 0.38$ ). The data provided in Table 4 show that more than half of the subjects in each group scored in the "not depressed" range of the BDI at follow-up. 20 per cent of the control group and 9.1 per cent of the Aricept group exhibited mild depressive symptomatology, 0 per cent and 18.2 per cent respectively moderate symptomatology and 10 per cent and 9.1 per cent severe symptomatology. These results are similar to those found at baseline.

#### **3.3.2.3. Behaviour and Mood Disturbance Scale**

Analysis of the two sub-scales of the BMDS showed that there was no significant difference between groups on the Mood Disturbance factor ( $F = 0.15$ , d.f. = 1, 19,  $p = 0.71$ ) while a significant difference was again found on the Apathy-Withdrawn factor ( $F = 14.58$ , d.f. = 1, 19,  $p = 0.001$ ). Table 4 and Chart 5 show that the control group reported higher mean scores ( $M = 30.91$ ) on this factor than did carers whose relative had commenced treatment with Aricept ( $M = 20.90$ ). This pattern of results reflects those obtained at baseline (see above).



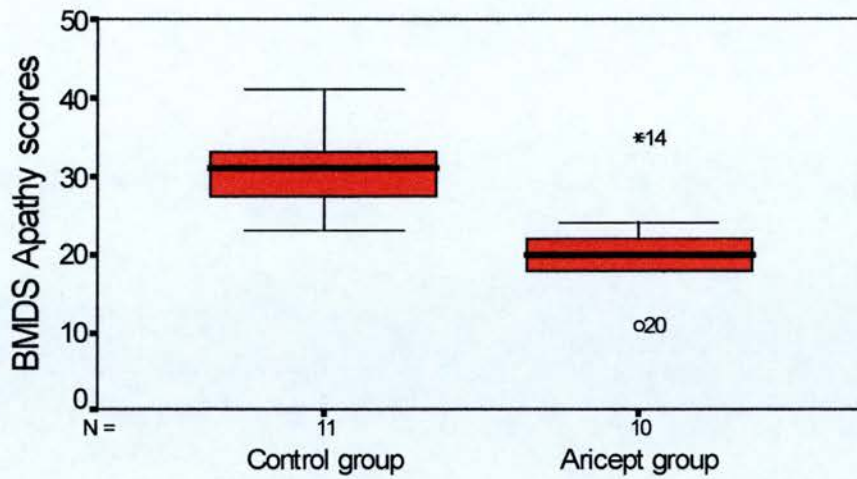


Chart 5. BMDS Apathy scores at follow-up

#### 3.3.2.4. Problem Checklist

Nonparametric statistical analysis showed that there was no significant difference between groups at follow-up on the Problem Checklist - Tolerance for Behaviours ( $U = 37.50$ , d.f. = 10, 11,  $p = 0.34$ ; two-tailed) but group responses did differ significantly on the Problem Checklist – Frequency of Behaviours ( $U = 21.00$ , d.f. = 10, 11,  $p = 0.02$ ; two-tailed). Table 4 and Chart 6 indicate that carers in the Aricept group ( $M = 17.60$ ) reported fewer problem behaviours in their relative than those in the control group ( $M = 31.91$ ) at follow-up. This reflects the pattern of scores seen at baseline (not significant).

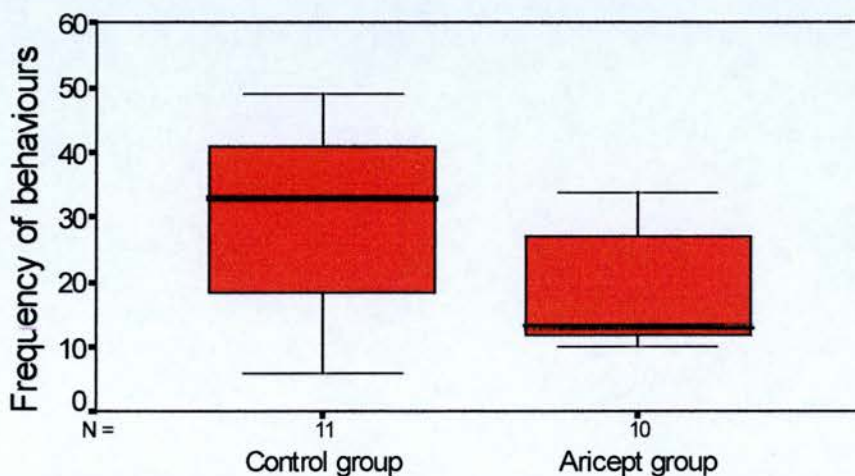


Chart 6. Frequency of problem behaviours (follow-up)

Similarly, Table 4 and Chart 7 show that carers in the control group reported less tolerance for their relatives' behaviours than did carers in the Aricept group although this difference was not significant at follow-up. This pattern of results also reflects that observed at baseline (not significant).

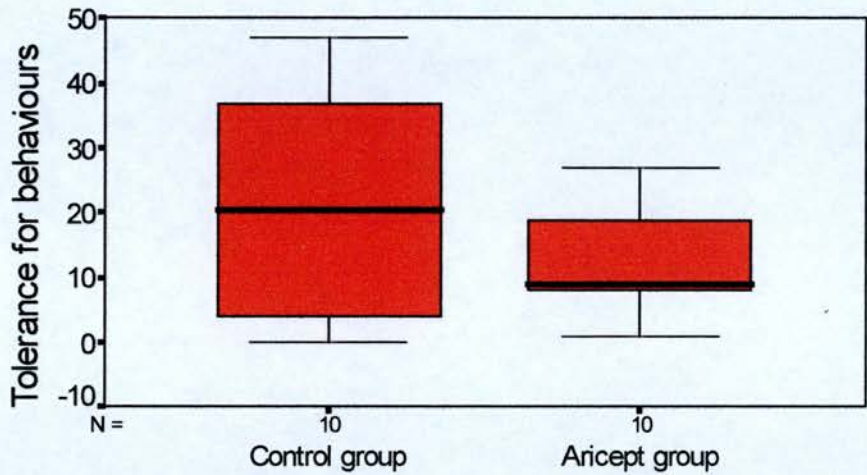


Chart 7. Tolerance for problem behaviours (follow-u

**3.3.2.5. Summary**

Statistical analysis indicated that primary caregivers whose dependants received Aricept did not report lower levels of stress/burden of care than carers in the control group (rejection of Hypothesis 6). Similarly, there was no significant difference between group BDI scores (rejection of Hypothesis 7). However, caregivers in the experimental group reported significantly lower scores on the Mood Disturbance sub-scale but not the Apathy/Withdrawn sub-scale, of the BMDS than those in the control group (partial acceptance of Hypothesis 8 but see baseline results). Caregivers in the Aricept group reported significantly lower levels of behavioural problems in their relative (acceptance of Hypothesis 9) but not how much these are problematic than the control group (rejection of Hypothesis 10).



### **3.4. Comparisons within groups**

#### **3.4.1. Relatives' Stress Scale**

A repeated measures analysis of variance (ANOVA) showed that control group total scores for the Relatives' Stress did not differ significantly over time ( $F = 1.01$ , d.f. = 1, 10,  $p = 0.34$ ). Similarly, no significant difference in experimental group total scores for the Relatives' Stress at baseline and follow-up was found ( $F = 0.30$ , d.f. = 1, 9,  $p = 0.60$ ).

Analysis of the three sub-scales of the RSS showed that there was no significant difference across time (baseline to follow-up) for the control group on responses to the Negative Feelings factor ( $F = 2.26$ , d.f. = 1,10,  $p = 0.16$ ), the Personal Distress factor ( $F = 0.85$ , d.f. = 1,10,  $p = 0.38$ ) or the Life Upset factor ( $F = 0.01$ , d.f. = 1, 10,  $p = 0.93$ ). Similarly, the experimental group scores on the Negative Feelings factor ( $F = 0.84$ , d.f. = 1,9,  $p = 0.38$ ), the Personal Distress factor ( $F = 0.22$ , d.f. = 1, 9,  $p = 0.30$ ) or the Life Upset factor ( $F = 0.18$ , d.f. = 1, 9,  $p = 0.68$ ) did not differ significantly over time.

#### **3.4.2. Beck Depression Inventory**

Nonparametric statistics indicated that there was no significant difference across time for control group ( $Z = 0.18$ ,  $N = 11$ ,  $p = 0.86$ ; two-tailed) or experimental group ( $Z = 1.00$ ,  $N = 10$ ,  $p = 0.32$ ; two-tailed) responses on the BDI.

#### **3.4.3. Behaviour and Mood Disturbance Scale**

Repeated measures analyses of variance (ANOVA) showed that there was no significant difference across time for the control group ( $F = 0.14$ , d.f. = 1,10,  $p = 0.71$ ) or the experimental group ( $F = 0.47$ , d.f. = 1, 9,  $p = 0.51$ ) on the Mood Disturbance factor of the Behaviour and Mood Disturbance Scale.

There was no significant difference across time for the control group ( $F = 0.18$ , d.f. = 1,10,  $p = 0.68$ ) or the experimental group ( $F = 0.77$ , d.f. = 1, 9,  $p = 0.40$ ) on the Apathy-Withdrawn factor.

**3.4.4. Problem Checklist**

Nonparametric statistical analysis showed that there was no significant difference between control group scores ( $Z = 1.25$ ,  $N = 11$ ,  $p = 0.21$ ; two-tailed) or experimental group scores ( $Z = 1.84$ ,  $N = 10$ ,  $p = 0.06$ ; two-tailed) across time on the Problem Checklist – Frequency of Behaviours. The data indicates that there is a trend for the experimental group report fewer problem behaviours in the patient on the Problem Checklist – Frequency of Behaviours (see Table 4 and Chart 8) after treatment with Aricept.

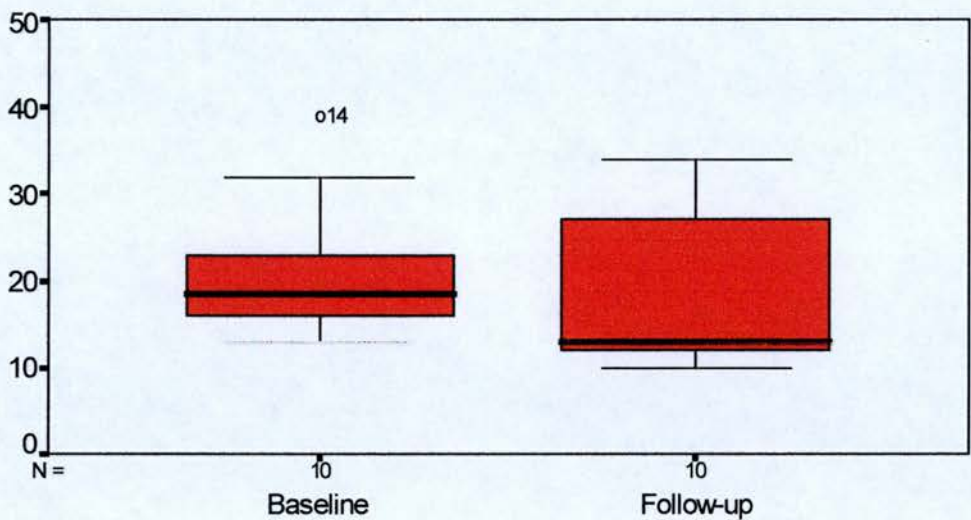


Chart 9. Frequency of problem behaviours (Aricept)

There was no significant difference between control group scores ( $Z = 0.84$ ,  $N = 11$ ,  $p = 0.40$ ) or experimental group scores ( $Z = 1.48$ ,  $N = 10$ ,  $p = 0.14$ ) across time on the Problem Checklist – Tolerance for Behaviours.

**3.4.5. Summary**

Statistical analysis shows that, following the prescription of Aricept to their dependent, primary caregivers did not report lower levels of stress/burden of care

(rejection of Hypothesis 1), lower levels of depression (rejection of Hypothesis 2) or lower levels of apathy/depression in their relative (rejection of Hypothesis 3). However, caregivers in the experimental group did report lower levels of behavioural problems in their relative (acceptance of Hypothesis 4) but not how much these were problematic (rejection of Hypothesis 5). No significant differences in control group scores on the measures administered were found across baseline to follow-up.

#### **3.4.6. Qualitative data**

Qualitative data was also collected from carers in the Aricept group by asking them the open-ended question “What difference, if any, have you noticed in your relative since they started Aricept?”.

Carers identified the following observations about their relatives since treatment commenced. Three carers commented that their relative was “calmer”, two that they were less “agitated” and two that they were “more alert”. Three carers stated that their relative was “perhaps a little less forgetful” with an example of this being that one patient remembered leaving his hat at Day Hospital - his carer stated that before treatment he would not have noticed it was missing let alone remember where he had left it! Three carers also commented that their relative was “more like their old self” and, finally, one carer noted that their relative was “less sensitive” (to perceived criticism) than before treatment.

#### **3.5. Linear regression analysis**

The degree to which the following measures in isolation predicted carer burden and depression was computed for baseline data across all subjects in order to allow comparison with previous studies: frequency of problem behaviours, tolerance for problem behaviours, mood and apathy in the patient (BMDS), deteriorating relationship with the patient, caregiving competency, carer’s physical health, appraisal of social support, time spent assisting and supervising the patient. Results are presented in Table 5.



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**Table 5.** General linear models analysis: analysis of predictors of burden and depression in carers.

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**Relatives' Stress Scale scores**

Source	F-ratio	Probability
Behaviour Checklist- Frequency of behaviours	10.55	0.01
Behaviour Checklist- Tolerance for behaviours	10.15	0.01
Behaviour Checklist- Tolerance x Frequency	11.89	0.01
BMDS – Mood sub-scale	4.57	0.04
BMDS – Apathy sub-scale	0.89	0.36
Caregiving competency	5.09	0.04
Carer's physical health	0.08	0.77
Appraisal of social support	0.02	0.88
Time spent assisting patient	4.55	0.04
Time spent supervising patient	1.22	0.28
Deteriorating relationship with patient	0.04	0.85

**Beck Depression Inventory scores**

Source	F-ratio	Probability
Behaviour Checklist- Frequency of behaviours	5.88	0.03
Behaviour Checklist- Tolerance for behaviours	0.79	0.38
Behaviour Checklist- Tolerance x Frequency	2.66	0.12
BMDS – Mood sub-scale	4.94	0.04
BMDS – Apathy sub-scale	0.53	0.48
Caregiving competency	1.93	0.18
Carer's physical health	1.31	0.27
Appraisal of social support	0.08	0.78
Time spent assisting patient	16.66	0.001
Time spent supervising patient	0.89	0.36
Deteriorating relationship with patient	0.31	0.59

---

The data presented in Table 5 indicate that frequency of behaviours, tolerance for behaviours and frequency by tolerance were highly predictive of burden in carers, as measured by scores on the Relatives' Stress Scale. Carer-rated estimates of the patient's mood disturbance were also predictive of burden unlike carer-rated estimates of apathy in the patient.

Frequency of behaviours, but not tolerance for behaviours or frequency by tolerance, was also predictive of depression in carers, as measured by scores on the Beck Depression Inventory. Carer-rated estimates of the patient's depressed/agitated mood, but not of apathetic mood, was also predictive of depression.

The data in Table 5 indicates that carer responses on the Problem Behaviour Checklist were more predictive of burden than depression.

Carers' rating of their competence as a caregiver was predictive of stress in carers but not depression. Time spent assisting the patient was predictive of both stress and depression in carers.

No significant associations were found between appraisal of social support, deteriorating relationship with the patient, carers' physical health or time spent supervising the patient with carer stress or depression.

## **CHAPTER FOUR:**

### **DISCUSSION**

#### **4.1. Limitations of the present study**

Perhaps the most obvious limitation of this study is the small number of subjects. As mentioned in Chapter Three, Cohen (1992) suggests that a total of 52 subjects were required to obtain statistical power for this study whereas only 21 subjects were obtained, 10 in the Aricept group and 11 in the control group. This indicates that it was unlikely that this study did not have sufficient to find significance between groups.

Despite the small sample size, groups did differ significantly in their responses to one measure at follow-up; the Problem Behaviour Checklist – Frequency of Behaviours. Other data indicated a trend towards significance. For example, the experimental group reported a non-significant decrease in frequency of problem behaviours on the Problem Behaviour Checklist – Frequency of Behaviours after their relative had commenced treatment with Aricept. Additionally, Table 4 and charts presented in Chapter Three, show that most of the mean scores on the RSS, the BMDS and the Problem Behaviour Checklist from the Aricept group decreased between baseline and follow-up whereas those of the control group tended to increase across time. These changes are in the directions predicted by the hypotheses (see Chapter One), suggesting that data from a larger sample may have resulted in support for more of the hypotheses of this study.

The small sample size also limited the use of linear regression analysis to estimate to what extent patient and carer variables (e.g. gender, relationship, age of carer and age of patient) were associated with outcome measures (e.g. scores on the RSS and BDI). This limited comparisons with previous research, particularly recent studies, the majority of which analysed their data using multiple regression analysis (e.g. Cullen et al., 1997; Graham et al., 1997; Zanetti et al., 1998).

This study did not have a double-blind design. Thus, both the researcher and the carer knew that the patients in the control group were receiving Aricept. It may

be that Aricept had little influence on the frequency of patient's behavioural disturbances (a significant difference between groups at follow-up) rather the positive beliefs and expectations on the part of the carer influenced their responses at follow-up. This may have in turn been influenced by positive beliefs and expectations of the influence of Aricept on the patient's behaviour on the part of the researcher which may have been apparent to the carers. Additionally, carers may have been able to divine the experimental hypotheses and may have been motivated to please the researcher by confirming these (Orne, 1969). Alternatively, the expectation of a change in their relative due to Aricept may have produced an experimental bias so carers perceived a change in the patient that had not in fact occurred (Kirsch, 1997). While the influence of expectations and beliefs on the outcome of this study were not examined directly, the findings from the present study are supported by those from double-blind, randomized trials which indicate that the behavioural features of Alzheimer's Disease are positively influenced by cholinergic treatments (Rogers et al., 1996, 1998; Raskind et al., 1997).

Another limitation of the present study may be sample bias. As mentioned previously, carers recruited through clinical services (e.g. Eagles et al., 1987; O'Connor et al., 1990) and those who elect to be interviewed at home (Dura & Kiecolt-Glaser, 1990), both of which were the case in this study, may manifest more morbidity than those from population-based samples. Thus, this sample may not be representative of the caregiving population as a whole.

Some limitations regarding the assessment instruments should be addressed. Patients' behavioural problems have been indirectly evaluated with an established measure (BMDS) that evaluates, along with depressive symptoms and signs, other aspects of behaviour such as language, space, orientation, wandering, insomnia and daily tasks such as reading and watching television (Greene et al., 1982). More recent and psychometrically sound measures of behaviour such as the BEHAVE-AD (Reisberg, Schneider, Doody et al., 1997) or the Neuropsychiatric Inventory (Cummings, 1997) would have provided a direct assessment of the patients' behavioural disturbances which may have allowed comparison with other studies. However, the BMDS was deemed an appropriate measure as this study was



concerned with carer stress, rather than measuring behavioural disturbance in people with dementia, and research indicates that it is the carer's appraisal of the caregiving situation and the patient, rather than actual symptoms, which are the important factor in determining carer stress (e.g. Hadjistavropoulos et al., 1994),.

Vitaliano et al. (1991), in their review of measures used among caregivers of individuals with dementia, criticised the basis of the three factors of the Behaviour and Mood Disturbance Scale and the Relatives' Stress Scale (Greene et al., 1982). They suggested that the use of factor analysis to establish the sub-scales of each scale was questionable, given the very small sample sizes ( $N = 38$ ) relative to the number of items (49). A second criticism of these scales is that the items tap distinct content domains, with no correspondence between measures of actual problems (objective burden) and appraised distress associated with specific caregiving experiences (subjective burden). The latter criticism is often levelled against measures of burden/stress in carers of people with dementia as the majority of measures incorporate items on both, examining feelings about giving care and the effect of caring on lifestyle (e.g. Fell, 1998). However, other measures of stress in this population seem equally, if not more questionable than the RSS. For example, statistical properties of measures are not always reported (see Knight, Lutsky & Macofsky-Urban, 1993), authors construct measures for their particular study (e.g. Mui & Murrow-Howell, 1993; Pruchno & Resch, 1989) or the length of well-known scales vary without adequate statistical properties being established for different versions (e.g. The Burden Interview; Zarit et al., 1985; Zarit et al., 1980; Zarit et al., 1986). Thus, the RSS was adopted for this study due to its ease of administration, relatively wide-spread use and the fact that its statistical properties, limited as they may be, were at least reported by the authors.

Another limitation of the present study is that the degree of the patient's cognitive impairment, as measured by the MMSE, was not analysed in relation to carer stress or depression. This data was not compared with carer responses as MMSEs on patients had not always been taken by their psychiatrists at baseline. However, as a lack of association between the patient's cognitive impairment and carer stress is a relatively consistent finding in the literature (e.g. Coen et al., 1997;

Greene et al., 1982; Mangone et al., 1993), it is likely that similar findings would have been found in this study .

Finally, it should be noted that the present study has focused upon the problems of caring as perceived by the carer, which were not confirmed by objective professional ratings. Coen (1996) suggests that the potentially distorting impact of stress on the carer's perception of the patient is a recurring problem in studies in which information is elicited primarily from the carer. However, Gilleard et al. (1982) suggest that this reflects a subjective reality which is an important determinant of a carer's willingness to continue to care: a factor of significance in view of the economic realities of service provision for elderly people with dementia. Additional support for this approach comes from studies which have shown that carer assessment of patient disturbances is often in line with direct assessments (e.g. compare Donaldson et al. [1998] and Greene et al. [1982]), while other studies indicate that it is the carer's appraisal of the caregiving situation and the patient, rather than actual symptoms, which are the important factor in determining carer stress (e.g. Hadjistavropoulos et al., 1994).

#### **4.2. Practical difficulties associated with the present study**

One difficulty associated with the present study was the time constraint of carrying out a piece of longitudinal research in a limited period of time. As described in Chapter Two, previous studies (e.g. Rogers et al., 1996) indicated that patients treated with donepezil showed significant improvement on cognitive and noncognitive measures at Week 12 but not Week Six for treatment. Given these findings, it was decided to administer follow-up measures to carers 12 weeks after their relative commenced treatment in this study. Ethics Committee permission was sought and obtained from Grampian and Fife in December and January respectively, leaving approximately five months to collect data. This allowed a two month period (January and February 1999) in which to collect all baseline data if follow-up data was to be collected within the time allocated for data collection (May 1999) for this thesis.

Before applying to Grampian and Fife Research Ethics Committees for permission for the above study and submitting a proposal for the study to the supervisor, discussion took place with Consultant Psychiatrists in Grampian and Fife regarding the feasibility of obtaining the number of subjects required for statistical power in the limited time available. Although these discussions indicated that accessing the required number of subjects for each group would not be problematic, several circumstances contributed to limiting the sample size.

Firstly, the protocol in Fife for treatment with Aricept is that a Consultant Psychiatrist recommends the use of this medication to the patient's General Practitioner (G.P.) who may or may not decide to act on this recommendation. Two potential carers in this study were rejected because their relative's General Practitioner chose not to prescribe Aricept although this course of treatment had been recommended by a Consultant Psychiatrist. This protocol for the use of Aricept contributed to a second, very practical problem given the time constraints of the study. At times, there were substantial delays between the author being informed by a Consultant Psychiatrist that they had recommended that a particular patient commence treatment with Aricept and the G.P. actually prescribing this medication.

As indicated above, the author depended on Consultant Psychiatrists for information regarding potential subjects for this study and all baseline data should have been collected in January and February 1999. Unfortunately, in this two month period, Psychiatry (Older Adults) in Fife saw substantially fewer patients than would normally occur in a two month period due to sick leave and commitments other than clinical work. This reduced the number of patients who may have recommended as suitable for Aricept and, consequently, for this study.

Grampian was approached as a source of potential subjects as they had obtained permission and funding to prescribe Aricept to 100 patients. However, it was decided to use the majority of this funding to treat people with dementia who were being cared for in hospitals or nursing homes and, therefore, not suitable for inclusion in this study (see Chapter Two for selection criteria).

### 4.3. Within-group results

The main objective of this study was to assess improvement in levels of stress of care and depression in primary caregivers of a relative with Alzheimer's Disease in relation to the prescription of Aricept (donepezil hydrochloride) to their dependent. A second objective was to assess if caregivers' ratings of frequency of behavioural disturbances, mood characteristics and their tolerance for behavioural disturbance improve following the patient's treatment with Aricept.

The study found no significant improvement over time in burden of care, measured by the Relatives' Stress Scale (RSS), or depression, measured by the Beck Depression Inventory (BDI), in the experimental group. There was no significant improvement in caregivers' ratings of frequency of and tolerance for behavioural disturbance (measured by the Problem Behaviour Checklist), or mood characteristics of the patient (measured by the Apathy-Withdrawn and Mood sub-scales of the Behaviour and Mood Disorder Scale; BMDS) following treatment with Aricept.

The data indicated a non-significant trend for carers in the Aricept group to report fewer behavioural disturbances (see Chapter Three: Chart 8) and more tolerance for such behaviours in their relative at follow-up, with mean scores on the RSS also decreasing over time (see Chapter Three; Table 4). Previous research has found that Aricept has a positive influence on patients' activities of daily living (ADL) ratings (Rogers et al., 1996, 1998) while Raskind et al. (1997) found that tacrine, another cholinergic treatment for AD, improved patients' scores on non-cognitive items of the ADAS (Rosen et al., 1984). Given that previous studies have found that frequency of, and tolerance for, behavioural disturbance are strong predictors of carer stress (e.g. Coen et al., 1997; Donaldson et al., 1998), the results from this study suggest that Aricept may have had a non-significant but positive influence on frequency of behavioural disturbances in the patient and carer tolerance for such behaviours which may, in turn, have had a beneficial effect on carer stress. This effect may have reached significance if the sample size had been larger. As hypothesised, the control group exhibited no significant differences in scores at baseline and follow-up.

The qualitative data (see Chapter Three) collected from carers in the Aricept group would seem to support the quantitative finding that these carers reported a decrease in behavioural disturbances in the patient after treatment commenced. The Behaviour Problem Checklist – Frequency of Behaviours includes questions on forgetfulness, demanding attention, asking continual questions and temper outbursts while qualitative comments from carers included relatives being “less agitated”, “calmer”, “less sensitive” and “more like their old self”.

While some of these qualitative responses would also appear to be related to mood improvements in the patient, no significant decrease in scores was reported by carers in the Aricept group on the Mood sub-scale of the BMDS. The mean score on this measure did decrease slightly over time (see Chapter Three; Table 4) suggesting that a significant decrease may have been found if the sample had been larger. Similarly, mean scores on the RSS indicate that stress in carers in the Aricept group decreased across time (see Chapter Three; Table 4). Previous studies have found that depression in patients is a predictor of carer stress (e.g. Donaldson et al., 1998; Draper et al., 1992; Greene et al., 1982) so it is possible that Aricept had a positive but non-significant effect on the patient’s mood which may, in turn, have had a beneficial effect on the carer’s level of stress.

Unfortunately, although three carers noted that their relative was “perhaps less forgetful” than before treatment, most patients had not been reviewed by their Consultant Psychiatrist at the time of follow-up. Thus, this study was unable to compare Mini Mental State Examination (MMSE) scores from before baseline with post-treatment and, thus, is unable to comment on whether or not these particular patients exhibited an objective improvement in memory, measured by MMSE scores, following treatment with Aricept.

The suggestions that Aricept may have a positive influence on behavioural disturbances and mood in the patient which, in turn, may have a beneficial effect on carer stress are very tentative given the non-significant trend in the data and the small sample size. However, these findings are of interest given that interventions which help to decrease carer stress may lessen demands on health care resources and encourage carers to continue to provide help (Donaldson et al., 1998). This is



particularly relevant given that studies of admission to acute or long-term care facilities consistently identify a breakdown in the carer's ability to provide assistance as the best single predictor of admission (e.g. Colerick & George, 1986; Young & Kahana, 1989). Pharmacological treatments for Alzheimer's Disease which improve the patient's cognitive functioning (e.g. Rogers et al., 1996, 1998) may be of benefit to the patient but not to the carer as the relationship between cognitive impairment in the patient and carer stress is complex (e.g. Prushno & Resch, 1989). On the other hand, a treatment for dementia which also positively influences behavioural disturbance and depressed/anxious mood in patients, features which are predictive of carer stress (e.g. Coen et al., 1997; Donaldson et al., 1998), may be beneficial to both the patient and the carer.

#### **4.4. Between-group results**

A second aim of this study was to compare ratings from self-identified primary caregivers of a related dependant with mild to moderate Alzheimer's Disease receiving Aricept with ratings from those whose relative was not receiving anti-dementia medication (the control group). This involved comparison of caregivers in the two groups to determine if the Aricept group reported lower levels of burden of care and depression than the control group at follow-up. Ratings of frequency of, and tolerance for, behavioural disturbance in the patient as well as mood characteristics of the dementia sufferer were also collected for comparison between groups.

Comparison of experimental and control group scores indicated that the Aricept group did not report significantly lower levels of burden of care and depression than the control group at follow-up. Tolerance for behavioural disturbance in the patient and mood characteristics of the dementia sufferer also did not differ between groups at follow-up. However, ratings of frequency of behavioural disturbance in the patient were significantly lower in the experimental group than the control group at follow-up (see Chapter Three: Table 4 and Chart 6). Although carers' rating of their dependants' levels of apathy/withdrawal also differed significantly between groups at follow-up (see Chapter Three: Chart 2), the finding

that this difference was also seen at baseline (see Chapter 3: Chart 5) indicated that it was not due to the influence of Aricept in the experimental group.

The data indicated a non-significant trend for carers in the Aricept group to report more tolerance for behavioural disturbances (see Chapter Three: Table 4 and Chart 7) and lower scores on the Mood Disturbance factor (see Chapter Three: Table 4) in their relative than carers in the control group at follow-up. Similarly, the Aricept group reported lower mean scores on the RSS than the control group at follow-up although these differences were not significant (see Chapter Three; Table 4). Generally, scores on most measures increased between baseline and follow-up in the control group whereas scores on most measures decreased over time in the Aricept group. These scores suggest that Aricept may have significantly reduced the frequency of patient disturbed behaviours and had a non-significant but positive influence on patient mood which may, in turn, have had a non-significant but positive effect on carer stress. These trends in the data may have reached significance if the sample size had been larger.

Carers in the control group reported significantly higher scores on the Life Upset factor of the RSS than the experimental group at baseline but not at follow-up (see Chapter Three: Table 4 and Chart 1). The Life Upset factor is considered to assess the disruption caring has on the caregiver's lifestyle and includes questions on the affect of caring on household routines, social life and sleep. This difference in scores may be influenced by the finding that patients in the control group had shown symptoms of dementia for less time than patients in the Aricept group and had, consequently, required assistance from their relative for less time than those in the Aricept group (see Chapter Three, Table 1). Although these differences between groups were non-significant, it is suggested that caregivers need time to adapt to changes in lifestyle necessitated by the role of caring and this burden abates as carers adjust to their role (see Pruchno & Resch, 1989). The higher scores (non-significant) reported by the control group for frequency of problem behaviour and tolerance for problem behaviour ((see Chapter Three, Table 4, Charts 3 and 4) at baseline may also be related to adaptation to the role of caring.



The results from this investigation differ from the pilot study which found that caregivers of relatives with dementia who were receiving Aricept reported significantly lower scores on the Relatives' Stress Scale (RSS; Greene et al., 1982) compared to carers whose relatives were not receiving antidementia medication. This difference may be explained, at least to some extent, by methodological factors in that control group patients in the present study and the pilot study may have been drawn from different populations (e.g. mild-moderate dementia vs. moderate-severe dementia), the age of patients and carers in the control and experimental groups in the pilot study differed significantly and controls in the pilot study were obtained from a support group rather than Day Hospital or Psychiatry (Older Adults).

Interestingly, while the number of formal services received by patients in the control and experimental groups did not differ significantly, carers in the control group were less satisfied with the number of services they received. It is tentatively suggested that the relative dissatisfaction with formal support that carers in the control group expressed, coupled with their slightly, non-significantly, higher levels of stress compared to the Aricept group at baseline and follow-up (see Chapter Three; Table 4) is in accordance with previous findings. For example, Gilhooly (1984a) found that it is not the amount of help given to the primary carer that contributes to stress, but how satisfied the carer is with the help given.

Possible reasons for dissatisfaction with services are discussed by Gilhooly et al. (1994) who suggest that, while it is acts of commission which are most problematic for carers (e.g. hitting, incontinence), the services provided in Britain are more closely matched to acts of omission (e.g. inability to bathe, get dressed). Thus, there may be a mismatch between the services provided (e.g. meals on wheels, home help, community nursing) and the needs of the carers (e.g. a service which prevents a person with dementia wandering the streets at night). However, it should be noted that in many of the studies reviewed by Gilhooly (1990), even when services were not shown to reduce stress, carers liked them and wanted them.

This latter finding is consistent with the positive feedback received from carers in the present study regarding the services received by their relative. Day Hospital was often singled out by carers as a service they particularly appreciated because it

provided them with “time out” from supervising their relative which, in turn, gave them time to engage in domestic activities such as shopping which they described as difficult to do with their relative present.

#### **4.5. Comparison with other studies**

As stated earlier, the baseline results from both groups were combined in order to carry out regression analysis. This allowed for comparison with previous studies of carer stress and depression. Unless otherwise stated, the following discussion relates to the combined baseline data from both the control group and the experimental group. Regression analysis was not performed on data pertaining to the carer’s relationship to the patient (e.g. husband, daughter), age of the carer or age of the patient due to the small sample size ( $N = 21$ ). Non-significant results are discussed when these are not in accordance with previous research findings.

##### **4.5.1. Stress in carers**

Comparison of total scores on the RSS indicates that the results from this study (see Chapter Three, Table 4) are roughly equivalent to those found by Greene et al. (1982) who administered the scale to primary carers of relatives diagnosed as suffering from dementia (Mean score = 27.22) with the control group in this study scoring slightly above this score, and the Aricept group scoring slightly below it, at both baseline and follow-up. Unfortunately, it is difficult to compare RSS total scores from this study with those found by Draper et al. (1992) and Eagles et al. (1987) as these authors used revised three point scale rather than the five point scale used by Greene et al. (1982) and this study. Using this method, RSS scores range from 0-30 rather than 0-60.

Taking this constraint into account the data presented by Draper et al. (1992) indicate that the total mean score for carers of relatives with dementia in their sample ( $M = 13.00$ ) is similar to that found in this study (RSS mean score = 26.36) and by Greene et al. (1982; see above). However, the results from Eagles et al.’s (1987) community sample indicate that carers of relatives with mild (RSS total mean score =

5.50) to moderate (RSS total mean score = 7.50) dementia obtained substantially lower total scores on the RSS than carers in this study, whose dependent had diagnoses of mild or moderate dementia, and that of Greene et al. (1982).

These different findings may be explained at least partially by sample bias with carers from population-based samples (Eagles et al., 1987; O'Connor et al., 1990) manifesting less morbidity than those recruited through contact with services or support groups, as was the case in this study and that of Draper et al. (1992). Similarly those who choose to be interviewed at home may report greater morbidity than those who elect to attend a hospital for assessment (Dura & Kiecolt-Glaser, 1990). Ninety per cent of carers in this study and 100 per cent of carers in Draper et al.'s (1992) study were interviewed at home.

Eagles et al. (1987) compared their sample with carers of a non-demented elderly relative and found that that carers of a relative with dementia obtained significantly higher scores on the RSS than the comparison group. This finding indicates that the sample in the present study would also obtain significantly higher scores than would be found in a comparison sample of carers for a non-demented relative, given that carers in the present study obtained substantially higher RSS total scores than those found in Eagles et al.'s (1987) supporters of dementia patients. No direct comparisons were made in this study as a control group of carers for an elderly relative with a non-dementing illness was not used.

However, the mean score obtained by Draper et al.'s (1992) comparison group (carers of an elderly stroke relative) was not significantly different to that found in the dementia carers group (11.30 vs. 13.00 respectively). This suggests that stroke and dementia caregivers experienced similar degrees of stress as measured by the RSS (see also Liptzin, Grob & Eisen, 1988 but see later).

***Behavioural disturbances in the patient:*** In the present study behaviour disturbance in the patient, rated by the carer, was the strongest predictor of carer stress, both in terms of frequency of disturbance, tolerance for disturbance and behaviour by tolerance. This is consistent with previous studies. For example, Greene et al. (1982) reported that it is the behavioural manifestations of dementia that relatives are least

able to tolerate. Similarly, Coen et al. (1997) found that frequency of behaviour disturbance in patients (assessed by the Dementia Behaviour Disturbance Scale, Baumgarten et al., 1990) was highly predictive of stress, and the frequency of behaviour by tolerance measure of even greater predictive value (see also Baumgarten et al., 1994; Cullen et al., 1997).

Mean scores indicated that the frequency of problem behaviours in patients, rated by carers using the Problem Behaviour Checklist – Frequency of Behaviours (Gilleard et al., 1984) were generally higher than those found by previous studies. For example, Brodaty & Hadzi-Pavlovic (1990) obtained a mean score of 16.20 on this measure in their sample of members of the Alzheimer's Disease and Related Disorders Society (ADARDS), New South Wales, Australia. This compares to mean scores in this sample of 21.10 (Aricept group) and 27.50 (control group) at baseline, 17.60 (Aricept group) and 30.91 (control group) at follow-up. This difference in scores may be explained to some extent by the difference in samples and methodology. That is, Brodaty & Hadzi-Pavlovic's (1990) did a postal survey of carers while carers were interviewed in this study. Secondly, subjects in Brodaty & Hadzi-Pavlovic's (1990) sample cared for relatives who suffered from mostly moderately severe dementia whereas in this study involved only carers of relatives with mild to moderate dementia.

Additionally, a support group may help reduce carers' stress and, secondly, as acknowledged by Brodaty & Hadzi-Pavlovic (1990), their sample may have responded in a way that they thought was required and/or those who did respond were psychologically healthier than those who did not return questionnaires. In reference to the above suggestion that membership of a support group may reduce carer stress, Graham et al. (1997) found that carers who had a higher level of knowledge about dementia experienced lower levels of depression and were more likely to make "positive comparisons" of their dependants' abilities. It is tentatively suggested that the carers in Brodaty & Hadzi-Pavlovic's (1990) sample may have had relatively high levels of knowledge about dementia gained through membership of ADARDS and this may have mediated their responses. In comparison, only one member of the current sample attended a support group.

***Depression in the patient:*** Comparison of scores on the BMDS Apathetic-Withdrawn sub-scale indicates that the results found in this study (see Chapter Three, Table 4) are roughly equivalent to those found by Greene et al. (1982;  $M = 24.95$ ) and Draper et al. (1992;  $M = 24.00$ ) with the control group in this study scoring slightly above these scores, and the Aricept group scoring slightly below it, at both baseline and follow-up. In contrast, scores on the Mood sub-scale of the BMDS in this study were substantially higher in this study compared to that found by Greene et al. (1982; Mean score = 10.68). This indicates that carers in this study rated their relative as more anxious and depressed than did Greene et al.'s (1982) sample. Unfortunately, it was not possible to compare BMDS sub-scale scores with the those of Draper et al. (1992) who did not present this data.

Linear regression analysis indicated that carer ratings of the patient's mood disturbance, measured by the Mood but not the Apathy/Withdrawn sub-scale of the BMDS, predicted levels of burden, or stress, in the carer, measured by the RSS. Several studies have suggested that carers who look after patients with more carer-rated depressive symptoms are at risk of experiencing high levels of stress (e.g. Donaldson et al., 1998; Draper et al., 1992; Greene et al., 1982).

The Apathy/Withdrawn sub-scale of the BMDS did not predict subjective burden, measured by the RSS, in carers in this study. This finding appears to be consistent with that of O'Connor et al. (1989) who found that disturbed-types of behaviours were associated with strain in relatives, while apathy-inertia problems were tolerated well. Gilleard et al. (1982) also concluded that different types of behavioural problems associated with dementia contribute unequally to the level of strain involved in such care, with the greatest source of stress in carers originating from problems of attentional and emotional demand.

Unlike the present study and those of Draper et al. (1992) and Greene et al. (1982), Donaldson et al. (1998) assessed patient dementia using an interviewer-rated (rather than a carer-rated) instrument, the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos et al., 1998). Their outcome was similar to those of the specified studies, which indicates that relatively short, carer-rated measures of patient



mood may obtain similar information to longer, interviewer-rated measures. However, it is of note that the Mood sub-scale of the BMDS is considered to measure signs of anxious and depressed mood, unlike the CSDD which focuses on depressive symptoms. Future studies may wish to investigate anxious and depressed mood in patients using separate measures in order to examine the relative influence of each on carer stress.

While a more objective index of patient depression, such as the CSDD, may have provided a more valid assessment of patient mood, previous studies have found that actual symptoms are relatively unimportant in relation to carer stress. For example, Hadjistavropoulos et al. (1994) found an association between patient mood and caregiver stress which disappeared when the caregivers' perception of patient mood was partialled out. In contrast, they found that a highly significant association of caregiver perception of patient mood and caregiver stress remained unaffected when the actual level of patient mood, assessed by the interviewer, was controlled. The authors (Hadjistavropoulos et al., 1994) suggest that these findings provide strong support for the hypothesis that actual deficits are relatively unimportant; rather, it is the carer's appraisal of mood which is the important factor in determining carer stress.

***Carer's personal resources:*** Regression analysis on the baseline data from all subjects indicated carers' ratings of their competence as caregivers were associated with carer burden, measured by the RSS. Low perceived competence was associated with higher levels of stress. This result supports the hypothesis of Pearlin et al. (1990) who suggested that low perceived competence is a risk factor for stress in carers. Little attention has been paid to this variable in studies of caregiver stress (see Section 4.4.2.).

No association was found between carers' ratings of their physical health status and stress. To the best of the author's knowledge, no previous studies have examined the effect of this variable on carer stress.

***Time spent assisting or supervising patient:*** Regression analysis on the baseline data from all subjects indicated carers' ratings of the number of hours daily that they spent assisting, but not supervising, the patient was predictive of carer stress, measured by the RSS. These findings seem to agree with those of Cullen et al. (1997) who found that levels of general time demands (e.g. those related to occupation or children, as well as those related to the caregiving role) were associated with carer stress, measured by the RSS, as well as psychiatric morbidity, measured by the General Health Questionnaire (Goldberg & Williams, 1988). Unfortunately, Cullen et al. (1997) did not examine the extent to which time demands associated solely with caring affected stress and psychiatric morbidity in their sample, so a direct comparison with the results in the present study is disallowed.

***Appraisal of support:*** When the baseline results from both groups were combined, appraisal of social support was not predictive of stress in carers. This result is not consistent with previous studies. For example, Zarit et al. (1980) found that more visits by family were associated with lower stress scores, while Coen et al. (1997) reported that subjective appraisal of supportive behaviours by family and friends was predictive of stress.

This inconsistency may be, at least in part, explained by different methodologies. For example, Coen et al. (1997) measured appraisal of support using the Social Support Appraisals (SS-A) Scale (Vaux, Phillips & Holly, 1986), which the authors report has good reliability and validity in community samples, whereas appraisal of social support in this study was assessed using a single question ("Would you like more help in caring for your relative from your family?").

***Relationship with the patient:*** As found in previous research (e.g. Morris et al., 1988), a deteriorating relationship with the patient did not correlate with increased levels of stress in carers. This point will be developed in a further section. On the other hand, the results from this study do not seem to support Horowitz & Shindelman's (1983) hypothesis that caregivers of frail elderly relatives who have, and maintain, positive feelings towards their relative report lower levels of perceived



stress. However, as this study did not collect quantitative data on the nature of the relationship between the patient and the carer before the patient became ill, a direct comparison between information on current relationship with the patient and previous relationship was not carried out.

#### **4.3.2. Depression in carers**

Studies of the prevalence of depression in carers of dementia sufferers mainly report prevalences of 30 per cent to 50 per cent (e.g. Williamson & Shulz, 1993; Pagel et al., 1985), as was found in this study (overall prevalence: baseline = 42.25 per cent, follow-up = 33.20 per cent). Compared to a point prevalence rate in adults in community samples of 5-9 per cent for women, 2-3 per cent for men (DSM-IV, 1994), the results of this study support previous findings that depression in carers of relatives with dementia is more frequent than in the population as a whole.

Previous studies have tended to find that most carers who report depressive symptoms on the Beck Depression Inventory fall into the categories of mildly or moderately depressed. For example, Zanetti et al. (1998) reported that 32 per cent of their sample had mild depression, 21.4 per cent had moderate depression and 8.7 per cent had severe depression while Haley, Levine, Brown & Bartolucci (1987) found most carers had mild depression with no-one in their study reporting severe symptoms. The pattern of depressive symptomatology found in this study seems to reflect these findings (see Chapter Three, Table 4).

The findings from this study and previous research indicate that a substantial number of caregivers may be experiencing depressive symptoms which could warrant intervention and treatment.

***Behavioural disturbances in the patient:*** Zanetti et al. (1998) found that high frequency of behavioural disturbances in patients is significantly associated with depressive symptoms in carers. This association was also found in the current study, although behaviour disturbance was less predictive of depression than of stress in carers. However, tolerance for behaviours or frequency by tolerance, was not

predictive of depression in carers. A review of the literature indicated that these measures have not been used to predict depression in carers in previous research.

***Depression in the patient:*** The results from this study support these findings in that linear regression analysis indicated that carer ratings of the patient's mood disturbance, measured by the Mood sub-scale of the BMDS, predicted depression in the carer, measured by scores on the Beck Depression Inventory. This finding appears to be consistent with those of Zanetti et al. (1998) who found that depression in carers was significantly associated with caregiver assessment of the patient's behavioural and mood disturbances.

Although both studies used the BMDS as a predictive measure, Zanetti et al. (1998) used the BMDS total scores in their analysis unlike the present study which compared scores on the Mood Disturbance sub-scale and Apathy/Withdrawn sub-scales of the BMDS only with the BDI (the Active/Disturbed Behaviour sub-scale was not administered and, therefore, total scores for the BMDS were not computed). Thus, carer depression in Zanetti et al.'s (1998) study may have been predicted to a great extent by carer responses on the Active/Disturbed Behaviour sub-scale given that behaviour disturbance in the patient, rated by the carer, is a strong predictor of carer stress (e.g. Baumgarten et al., 1994; Coen et al., 1997; Cullen et al., 1997; Greene et al. (1982), rather than responses on the Mood Disturbance sub-scale and Apathy/Withdrawn sub-scales. This hypothesis could not be investigated as data pertaining to individual sub-scale scores was not presented by Zanetti et al. (1998).

***Carer's personal resources:*** Zanetti et al. (1998) found associations between the caregiver's personal resources (physical health and caregiving competence) and depressive symptomatology. They suggest that patients' behavioural disturbances could act as a trigger for the development of depressive symptoms in more vulnerable carers, whose personal resources are poor. Similar results were obtained by Haley et al. (1987), who found that caregiver appraisals of themselves as unable to manage their dependants' disabilities and behavioural disturbances, were significantly related to higher levels of carer depression. These associations were not found in the present

study (but see earlier) although the same methodology was used for these variables. This discrepancy may be due to the small sample size in this study and/or to the finding that carers in this study rated their care-giving competence and physical health as higher than did the subjects in Zanetti et al.'s (1998) and Haley et al.'s (1987) studies.

Recently it has been demonstrated that caregivers who had more knowledge of AD had a lower rate of depression and exhibited a positive association between level of knowledge and feelings of competency (Graham et al., 1997). Zanetti et al. (1998) suggest that, given these findings, caregivers with a low level of knowledge about dementia may find it difficult and distressing to manage relatives with dementia and may benefit from educational programmes targeted to their needs. Unfortunately, carer's knowledge of dementia was not assessed in the present study.

***Time spent assisting or supervising patient:*** Regression analysis on the baseline data from all subjects indicated carers' ratings of the number of hours daily that they spent assisting, but not supervising, the patient was predictive of carer depression, measured by the BDI. These findings agree with those of Zanetti et al. (1998) who found that a higher number of hours per day of assistance but not supervision was associated with depressive symptomatology in carers.

***Relationship with the patient:*** Unlike the present study, previous research has found that a deteriorating relationship with the patient correlates with increased levels of depression in carers (e.g. Brodaty & Hadzi-Pavlovic, 1990; Morris et al., 1988). This may be due to methodological differences as the aforementioned studies examined levels of stress and psychological morbidity in spouse caregivers only, whereas the present study also involved adult children who identified themselves as the primary caregiver of a parent with dementia. No experimental studies seem to have examined the influence of deteriorating relationship with the dementing parent on depression in caregivers who are adult children of the patient.

#### **4.6. Illustrative case studies**

Given the paucity of significant findings in this study, two case studies are provided to illustrate the nature of the data reported from subjects. These case studies provide information on aspects of caring which the carers reported as stressful and the changes observed in one patient after treatment with Aricept. This information and sociodemographic details from the carers are discussed in relation to the caregiving literature.

##### **4.6.1. Case study 1: The “stressed” carer (Aricept group)**

This case study was select for presentation as it illustrates differences across time in a patient in the experimental group and a reduction in stress in the carer as reported by the carer, MW who was the daughter of the patient. The information in this case study was deemed as representative of data obtained from other adult daughter caregivers in this study. It also illustrates the caregiver’s reported difficulties with balancing other demands with those of caring, a deteriorating relationship with the patient and the beneficial effect of the provision of formal services.

MW, aged 52 years, cared for her mother (age 79 years) who she estimated first started to show signs of Alzheimer’s Disease about three years previously. MW had first started helping her mother in practical matters approximately one year after she noticed memory problems and other symptoms of dementia occurring. MW lived with her partner and adult son in the same village as her mother and had a full-time job as a cleaner.

As mentioned above, MW did not co-reside with her mother but rather visited at least once per day to supervise her mother and to carry out practical tasks (e.g. washing, cleaning). She described these daily visits as very stressful for a variety of reasons. Firstly, she tended to spend at least two hours per day with her mother which, given she had a full-time job, left very little time to spend with her partner, on hobbies/pastimes, or going out socially. Secondly, MW stated that while her previous relationship with her mother had been good, she described her as “not my mother any

more” since the disease had progressed and stated that their relationship had deteriorated considerably since the onset of her illness. She found the changes in her mother upsetting and difficult to accept – indeed, she stated that she was angry about the way her mother was now. MW also told me that when she was at work or at home she always worried about accidents happening to her mother or her forgetting something important (e.g. locking the door at night) – indeed, she described herself as constantly “uptight” with worry, which she tended to take out on her partner. Her son also visited his grandmother twice a week to provide help and to give his mother a break.

MW’s mother received input from Psychiatry, Community Nursing and Social Work. She described Community Nursing as particularly useful, as knowing that someone else was “keeping an eye” on her mother allowed her to relax a little. She wished for more assistance in caring for her mother from formal services: specifically, a Home Carer to help with practical matters, and Day Hospital support to provide a structure to her mother’s week.

By follow-up these services had been implemented, as had Meals on Wheels. MW exhibited fewer signs of stress, describing things as “a lot better”. She told me that, because of being less stressed about the situation herself, she was more patient with her mother and generally felt that she was dealing with her behavioural and mood disturbances better. She was also able to spend more time with her partner and she had gone out socially more often since these services had started than she had in the year before baseline.

Her mother had also commenced treatment with Aricept. MW stated that the only difference she had seen in her mother which she ascribed to the medication was that she was calmer and less agitated. The latter referred to her mother’s previous tendency to want to be out during the day (e.g. shopping) whereas after treatment with Aricept commenced she was more content to stay at home alone. This was a positive improvement according to MW as she had worried a lot about her mother taking the wrong bus home or getting lost in a shopping centre.

MW’s responses to the measures administered indicated that her mother was quite apathetic and withdrawn at baseline and follow-up. There was no difference in



her assessment of her mother's behaviour on the Apathy-Withdrawn and Mood subscales or MW's score on the BDI over time ("not depressed" at baseline and follow-up). However, she reported fewer problem behaviours and more tolerance for these behaviours on the Behaviour Checklist at follow-up. Her total score on the Relatives' Stress Scale reduced substantially over time. MW did described herself as "much less stressed" and, indeed, presented as more relaxed during our follow-up interview. She ascribed the aforementioned improvements as due to the formal support she was receiving as well as the effects of Aricept on her mother's behaviour.

The literature indicates that carers who are daughters tend to report the most stress (Coen et al., 1997; Grafstrom et al., 1994). Gilhooly (1984) argues that this may be due to women, especially those who are closely related to the patient, showing greater emotional over-involvement and being less able to step back from their role to view caregiving as a problem-solving task. While this may explain some of MW's stress at baseline another hypothesis is that women may simply be more likely to admit to distress than men Gilhooly (1984). While some studies have found that work outside the home can be a protective factor against carer stress (e.g. Morrissey et al. (1990), MW found the conflicting demands of juggling work, her own home life and visiting her mother a great source of stress (see Pearlin et al., 1990). As has been found previously (e.g. Bass et al., 1996; Collins & Jones, 1997 but see Gilleard et al., 1984), receipt of formal services seemed to be associated with an improvement in MW's wellbeing. Additionally, she regarded this support very positively – studies have found that it is not the provision of services per se that has a beneficial effect on psychological well-being in carers but the positive appraisal of such support (e.g. Coen et al., 1997; George & Gwyther, 1986; Vaux et al., 1986).

A further factor which seemed to be contributing to MW's relatively high levels of stress at baseline was her evaluation that her relationship with her mother was deteriorating due to her mother's illness (see Gilleard et al., 1984; Horowitz & Shindelman, 1988). While their relationship did not seem to improve between baseline and follow-up, MW appeared more able to accept the loss of intimacy

possibly because her reduced level of stress allowed her to cope better overall with the situation.

#### **4.6.2. Case study 2: The “unstressed” carer (control group)**

This case study was select for presentation as it illustrates how tolerance for behavioural disturbance and depressed mood in the patient may be a protective factor against stress or depression in the carer. It also shows how attitudes towards the patient and caring itself may help carers cope with the demands of caregiving. While the patient in this case study did not receive Aricept, the data collected provides a contrast with the first case study. It also provides some insight into the diversity of responses obtained in this study and how variables such as those specified above, as well as other factors such as relationship with the patient and support from a spouse, may influence caregiver well-being.

AF, aged 58 years, cared for his mother who was aged 85 years. AF was married, without children. He was not in paid employment. He reported that he had noticed memory problems or other symptoms of dementia in his mother about four years previously, estimating that he had started to provide practical assistance about three years ago. Approximately 12 months before baseline he had arranged for his mother to live with him and his wife.

AF regarded co-residence as reducing his level of stress, describing the period leading up to his decision to move his mother to his house as extremely stressful due to her behaviour. For example, she would telephone him four or five times per day usually to ask him to visit in order to do a task for her (e.g. check that her doors were secure) or, alternatively, she would say nothing on the telephone. In the latter case, AF became very concerned and drove to visit his mother (who lived about five miles away) in order to check if she was alright. These calls occurred throughout the day and night. He told me that he found these demands on his time, coupled with his worry about how his mother was coping when alone, so stressful that he decided it would be easier if she lived with him. His wife, who was also unemployed, supported him in this decision and helped him with caring for his mother. His wife was present

at the interviews and our discussion indicated that she supported him both practically and emotionally with caring.

AF told me that he had always had a very good relationship with his mother and did not regard it as deteriorating at all since the onset of her illness.

His mother attended day hospital two days per week and was monitored by a Consultant Psychiatrist (Old Age Service). He regarded the latter service as excellent and stated that it offered him “time out” from the demands of caring. He knew of the local Carer’s Support Group but had never attended, stating that he and his wife were unable to leave his mother unattended and no other members of his family (i.e. his brothers or sisters who lived locally) were willing to help in this matter. He reported that he was unable to visit family and friends or engage in hobbies outside the home as often as he would have liked due to caring but did not seem particularly despondent about this as he had several home-based hobbies (e.g. keeping parrots) which he enjoyed. Generally, AF and his wife seemed to have organised their lives around caregiving and did not seem resentful of the changes in their lifestyle due to providing care.

AF described a stoical approach towards coping. For example, he tended to ascribe his mother’s behaviour (e.g. wandering at night, needing help with activities of daily living, forgetfulness) and moods (e.g. apathy and confusion) as due to her illness, stating that she “can’t help it” and she “doesn’t do it on purpose”.

AF’s responses to the Behaviour and Mood Disturbance Scale indicated that mother’s behaviour was quite apathetic and withdrawn, and her mood deteriorated from baseline to follow-up. He reported many behavioural disturbances on the Behaviour Checklist, most of which were acts of omission (e.g. inability to carry out tasks such as dressing independently; see Gilhooly, 1984) rather than “demand-type” problems (such as verbal abuse, aggression; see Gilleard et al., 1982). However, his responses on the Behaviour Checklist – Tolerance for Behaviours subscale indicated that he was highly tolerant of these behaviours. His scores on the Relatives’ Stress Scale did not differ over time and analysis of the RSS sub scales indicated that most of his responses fell into the Personal Distress category (e.g. worry about accidents happening to his mother, feeling that he would never get a break). There was no

difference in scores on the Beck Depression Inventory ("not depressed") at baseline and follow-up. At follow-up, AF told me that nothing had changed, he and his wife continued to "just get on with it [caring]".

The literature indicates that AF's relatively low self-reported levels of stress and depression may have been mediated by his relationship to the patient. Studies which have compared carer stress in daughters, sons, husbands and wives of the patient have found that sons generally report the least stress (e.g. Coen et al., 1997; Zanetti et al., 1998). Zarit et al. (1986) postulated that this difference may be due to men having different strategies for coping with everyday problems which enables them to distance themselves more. Qualitative information indicated that AF did indeed have an instrumental, or stoical, approach to coping; for example, he tended to ascribe his mother's behavioural disturbances to her illness (see above). This approach may also explain the finding that, while AF spent the most time of any respondent in this sample assisting his relative on a daily basis (about four hours), he did not report a relatively high level of depression - Zanetti et al. (1998) suggest that more hours of assistance predicts higher levels of depression in carers.

High frequency of behaviour disturbance has been found to be highly predictive of carer stress (e.g. Zarit et al., 1985) and depressive symptoms (e.g. Zanetti et al., 1998). AF's scores do not reflect these findings, possibly because of his high tolerance for his mother's behaviour disturbance (see Coen et al., 1997).

Other factors which may have contributed to his relatively low levels of reported stress and depression may be his relationship with his mother, which he regarded as not deteriorating (see Gilleard et al., 1984; Horowitz & Shindelman, 1983); practical and emotional support from his wife (see Coen et al., 1997); rating himself as a good carer (see Haley et al., 1987; Zanetti et al., 1998) and having no conflicting demands (e.g. children, work) on his time (see Pearlin et al., 1990). The author tentatively speculates, following Connor et al. (1990) and Collins & Jones (1997), that AF found gratification in the caregiving role as it gave him a purpose in life. This suggestion is supported by the finding that he and his wife had previously carried for her father and aunt, who also suffered from dementia. AF also voiced the

opinion that children were responsible for looking after elderly parents, stating that his mother was “no bother” and he did not see any reasons for giving up care.

#### **4.7. Conclusion**

Statistical analysis of the data indicated that primary caregivers whose dependants received Aricept reported significantly lower levels of behavioural problems in their relative at follow-up. Similarly, behavioural disturbance in the patient was significantly lower in the experimental group than the control group at follow-up. While other results indicated no significant differences between groups or within groups at follow-up, trends in the data were generally in the direction predicted by the hypotheses. This suggests that the results from this study may have reached significance if sufficient subjects had been recruited.

Linear regression analysis of all baseline data ( $N=21$ ) indicated that the data from this study is generally similar to that reported by previous studies. For example, frequency of behavioural disturbance, tolerance for behavioural disturbance and the patient's mood disturbance were found to be highly predictive of stress in carers. Carers' ratings of their caregiving competency and the time they spent assisting the patient daily were also predictive of stress. Depression was predicted by frequency of behavioural disturbance, patient mood and the time spent assisting the patient daily. Differences between the results from this study and previous findings can, at least in part, be explained in relation to methodological issues.



## **CHAPTER FIVE:**

### **REFERENCES**

- Absher, J.R. & Cummings, J.L. (1994). Cognitive and noncognitive aspects of dementia syndromes: An overview. In A. Burn and R. Levy (Eds), Dementia. Chapman & Hall Medical: London.
- Argyle, N., Jestice, S. & Brook, P. (1985). Psychogeriatric patients: Their supports' problems. Age and Ageing, 14, 335-360.
- Bass, D.M., Noelker, L.S. & Rechlin, L.R. (1996). The moderating influence of service use on negative caregiving consequences. Journal of Gerontology, 51, S121-S131.
- Baumgarten, M. (1989). The health of persons giving care to the demented elderly: A critical review of the literature. Journal of Clinical Epidemiology, 45, 1137-1148.
- Baumgarten, M., Battista, R.N., Infante-Rivard, C., Hanley, J.A., Becker, R. & Gauthier, S. (1992). The psychological and physical health of family members caring for the elderly person with dementia. Journal of Clinical Epidemiology, 45, 61-70.
- Baumgarten, M, Becker, R. & Gauthier, S. (1990). Validity and reliability of the Dementia Behaviour Disturbance Scale. Journal of the American Geriatric Society, 38, 455-460.
- Beck, A.T., Ward, C.H., Mendelson, M., Mock, J. & Erbaugh. (1961). An inventory for measuring depression. Archives of General Psychiatry, 4, 561-571.
- Berg, L., Miller, J.P., Baty, J., Rubin, E.H., Morris, J.C. & Figiel, G. (1992). Mild senile dementia of the Alzheimer type: Evaluation of intervention. Annals of Neurology, 31, 242-249.
- Bianco, M. (1995). Considerations sobre el demente y su cuidador en la enfermedad de Alzheimer. Gerontologia, 11, 53-56. Cited in: Zanetti, O, Frisoni, G.B., Bianchetti, A., Tamanza, G., Cigoli, V. & Trabucchi, M. (1998). Depressive symptoms of Alzheimer caregivers are mainly due to personal rather than patient factors. International Journal of Geriatric Psychiatry, 13, 358-367.

- Bradburn, N.M. (1969). The Structure of Psychological Well-being. Chicago: Aldine.
- Braithewaite, V. (1992). Caregiving burden: Making the concept scientifically useful and policy relevant. Research into Ageing, 14, 3-27.
- Brodaty, H. & Hadzi-Pavlovic, D. (1990). Psychosocial effects on carers living with persons with dementia. Australian and New Zealand Journal of Psychiatry, 24, 351-361.
- Cavallo, M.C. & Fattore, G. (1994). Il costo sociale della malattia di Alzheimer: Metodologia e risultati di una indagine preliminare. Mecosan, 10, 12 -23. Cited in: Zanetti, O, Frisoni, G.B., Bianchetti, A., Tamanza, G., Cigoli, V. & Trabucchi, M. (1998). Depressive symptoms of Alzheimer caregivers are mainly due to personal rather than patient factors. International Journal of Geriatric Psychiatry, 13, 358-367.
- Clipp, E. & Moore, M. (1990). Caregiver time use: An outcome measure in clinical trial research in Alzheimer's disease. Clinical and Pharmacological Therapy, 58, 228-236.
- Coen, R.F. (1996). Individual QoL and assessment by carers or "proxy" respondents. In C.A. O'Boyle, H.M. McGee & C.R.B. Joyce (Eds), Individual Quality of Life: Approaches to Conceptualisation and Measurement. Harwood Academic: Reading.
- Coen, R.F., Swanwick, G.R., O'Boyle, C.A. & Coakley, D. (1997). Behavioural disturbance and other predictors of carer burden in Alzheimer's disease. International Journal of Geriatric Psychiatry, 12, 331-336.
- Cohen, J. (1992). A Power Primer. Psychological Bulletin, 112, 155-159.
- Collins, C. & Jones, R. (1997). Emotional distress and morbidity in dementia carers: A matched comparison of husbands and wives. International Journal of Geriatric Psychiatry, 12, 1168-1173.
- Coope, B., Ballard, C., Saad, K., Patel, A., Bentham, P., Bannister, C., Graham, C. & Wilcock, G. (1995). The prevalence of depression in the carers of dementia sufferers. International Journal of Geriatric Psychiatry, 10, 237-242.

- Coppel, D.B., Burton, C., Beker, J. & Fiore, J. (1985). Relationships of cognitions associated with coping reactions to depression in spousal caregivers of Alzheimer's disease patients. Cognitive Therapy Research, 9, 253-266.
- Crismon, M.L. (1994). Tacrine: First drug approved for Alzheimer's disease. Annals of Pharmacotherapy, 28, 744-751.
- Cullen, J.S., Grayson, D.A. & Jorm, A.F. (1997). Clinical diagnoses and disability of cognitively impaired older persons as predictors of stress in their carers. International Journal of Geriatric Psychiatry, 12, 1019-1028.
- Cummings, J.L. (1997). The Neuropsychiatric Inventory: Assessing psychopathology in dementia patients. Neurology, 48 (Suppl. 6), 10-16.
- Davies, P. & Maloney, A.J. (1976). Selective loss of central cholinergic neurons in Alzheimer's disease. Lancet, 2, 1403.
- Davies, K.L., Thal, L.J., Gamzu, E.R. et al., (1992). A double blind placebo controlled multi-centre study of tacrine for Alzheimer's disease. New England Journal of Medicine, 327, 1253-1259.
- Deimling, G.T. & Bass, D.M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. Journal of Gerontology, 41, 778-784.
- Diagnostic and Statistical Manual of Mental Disorders – 4<sup>th</sup> Edition. (DSM-IV) (1994). Washington, DC.: American Psychiatric Association.
- Donaldson, C., Tarrier, N. & Burns, A. (1997). The impact of symptoms of dementia on caregivers. British Journal of Psychiatry, 170, 62-68.
- Donaldson, C., Tarrier, N. & Burns, A. (1998). Determinants of carer stress in Alzheimer's Disease. International Journal of Geriatric Psychiatry, 13, 248-256.
- Draper, B.M., Poulos, R.G., Poulos, C.J. & Erlich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. Journal of the American Geriatric Society, 40, 896-901.
- Dura, J.R. & Kiecolt-Glaser, J.K. (1990). Sample bias in caregiving research. Journal of Gerontology, 45, 200-204.

- Dura, J.R., Stukenberg, K.W. & Kiecolt-Glaser, J.K. (1991). Anxiety and depressive disorders in adult children caring for demented parents. Psychology and Aging, 6, 467-473.
- Eagles, J.M., Craig, A., Rawlinson, F. et al. (1987). The psychological well-being of supporters of the demented elderly. British Journal of Psychiatry, 150, 293-298.
- Ernst, R.L. & Hay, J.W. (1994). The US economic and social costs of Alzheimer's disease revisited. American Journal of Public Health, 84, 1261-1264.
- Farlow, M., Gracon, S.I., Hershey, L.A., Lewis, K.W., Sadowsky, S.H. & Dolan-Ureno, J. (1992). A controlled trial of tacrine in Alzheimer's disease. Journal of the American Medical Association, 268, 2523-2529.
- Fell, M. (1998). Care of older people: A comment on measures of carer burden. Clinical Psychology Forum, 117, 28-29.
- Fitting, M., Rabins, P., Lucas, M. & Eastman, J. (1986). Caregivers for dementia patients: A comparison of husbands and wives. Gerontologist, 26, 248-252.
- Folstein, M.F., Folstein, S.E. & McHugh, P.R. (1975). Mini Mental State. A practical method for grading the cognitive state of subjects for the clinician. Journal of Psychiatric Research, 12, 189-198.
- Fratiglioni, L., Forsell, Y., Torres, H.A. & Winblad, B. (1994). Severity of dementia and institutionalisation in the elderly: Prevalence data from an urban area in Sweden. Neuroepidemiology, 13, 79-88.
- Friedhoff, L.T. & Rogers, S.L. (1997). Donepezil lengthens time to loss of activities of daily living in patients with mild or moderate Alzheimer's disease – results of a preliminary evaluation. Neurology, 48, 1002-1026.
- Gallagher-Thompson, D., Brooks, J.O., Bliwise, D., Leader, J. & Yesavage, J.A. (1992). The relations among caregiving stress, "sundowning" symptoms, and cognitive decline in Alzheimer's disease. Journal of the American Geriatric Society, 40, 807-810.
- Giacobini, E. & Becker, R. (1989). Present progress and future developments in the therapy for Alzheimer's disease. In K. Iqbal, H.M. Wisniewski & B. Winblad (Eds), Alzheimer's Disease and Related Disorders, pp.1121-1154. New York: Alan R. Liss Inc.

- George, L.K. (1994). Caregiver burden and well-being: An elusive distinction. The Gerontologist, 34, 6-7.
- George, L.K. & Gwynter, L.P. (1986). Caregiving well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist, 26, 253-259.
- Gerritson, J.C. & van der Ende, P.C. (1994). The development of a care-giving burden. Age and Ageing, 23, 483-491.
- Gilhooly, M.L.M. (1984a). The social dimensions of senile dementia. In R Taylor & A. Gilmore (Eds), Current Trends in British Gerontology, pp. 61-76. London: Gower Press.
- Gilhooly, M.L.M. (1986). Senile dementia: Factors associated with care-givers preference for institutional care. British Journal of Medical Psychology, 56, 165-171.
- Gilhooly, M.L.M. (1990). Do Services Prevent a Delay in Institutionalisation of People with Dementia? Research Report 4, Dementia Services Development Centre, University of Stirling.
- Gilhooly, M.L.M., Sweeting, H.N., Whittick, J. & McKee, K. (1994). Family care of the dementing elderly. International Review of Psychiatry, 6, 29-40.
- Gilleard, C.J. (1984). Living with Dementia: Community Care of the Elderly Mentally Infirm. Croon Helm.
- Gilleard, C.J., Belford, H., Gilleard, E., Whittick, J.E. & Gledhill, K. (1984a). Emotional distress amongst the supporters of the elderly mentally infirm. British Journal of Psychiatry, 145, 172-177.
- Gilleard, C.J., Boyd, W.D. & Watt, G. (1982). Problems caring for the elderly mentally infirm at home. Archives of Gerontology and Geriatrics, 1, 151-158.
- Gilleard, C.J., Gilleard, E., Gledhill, K. & Whittick, J. (1984b). Caring for the elderly mentally infirm at home: A survey of the supporters. Journal of Epidemiology and Community Health, 38, 319-325.
- Goldberg, D. (1978). Manual of the General Health Questionnaire. Windsor, Berks: NFER-Nelson.



- Grafstrom, M., Fratiglioni, L. & Winblad, B. (1994). Caring for an elderly person: Predictors of burden in dementia care. International Journal of Geriatric Psychiatry, 9, 373-379.
- Grafstrom, M. & Winblad, B. (1995). Family burden in the care of the demented and non-demented elderly. A population-based study. Alzheimer's Disease and Associated Disorders, 9, 78-86.
- Graham, C., Ballard, C. & Sham, P. (1997). Carers' knowledge of dementia, their coping strategies and morbidity. International Journal of Geriatric Psychiatry, 12, 931-936.
- Greene, J.G., Smith, R., Gardiner, M. & Timbury, G.C. (1982). Measuring behavioural disturbance of elderly dementing patients in the community and its effect on relatives: A factor analytic study. Age & Ageing, 1, 121-126.
- Greene, J.G. & Timbury, G.C. (1979). A geriatric psychiatry hospital service: A five-year review. Age and Ageing, 8, 49-53.
- Hadjistavropoulos, T., Taylor, S., Tuokko, H. & Beattie, B.L. (1994). Neuropsychological deficits, caregivers' perception of deficits and caregiver burden. Journal of the American Geriatric Society, 42, 308-314.
- Haley, W.E., Levine, E.G., Brown, S.L. & Bartolucci, A.A. (1987). Stress, appraisal, coping and social support as predictors of adaptational outcome among dementia caregivers. Psychology and Aging, 2, 323-330.
- Ham, R.J. (1997). Confusion, Dementia and delirium. In R.J. Ham & P.D. Sloane (Eds), Primary Care Geriatrics: A Case-Based Approach, 3<sup>rd</sup> Edition. St. Louis, Baltimore: Mosby Yearbook.
- Ham, R.J. (1997). Clinical efficacy of donepezil hydrochloride in patients with Alzheimer's disease. Advances in Therapy, 14, 223-233.
- Harper, S. & Lund, D.A. (1990). Wives, husbands and daughters caring for institutionalised and non-institutionalised dementia patients: Towards a model of caregiver burden. International Journal of Aging and Human Development, 30, 241-262.
- Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. The Gerontologist, 25, 612-617.

- Horowitz, A. & Shindelman, L.W. (1983). Reciprocity and affection: Past influences on current caregiving. Journal of Gerontological Social Work, 5, 5-20.
- Howell, D.C. (1982). Statistical Methods for Psychology. Boston, MA.: PWS Publishers.
- Jost, B.C. & Grossberg, G.T. (1995). The natural history of Alzheimer's disease: A brain bank study. Journal of the American Geriatric Society, 43, 1248-1255.
- Kavanagh, S.M., Schneider, J., Knapp, M.R.J., Beecham, J.K. & netten, A. (1995). Elderly people with dementia: Costs, effectiveness and balance of care. In M.R.J. Knapp (Ed.), The Economic Evaluation for Mental Health Care. Aldershot: Arena.
- Kay, D.W.K., Beamish, P. & Roth, M. (1964). Old age mental disorders in Newcastle-upon-Tyne. British Journal of Psychiatry, 110, 146.
- Kiecolt-Glaser, J.K., Dura, J.R., Speicher, C.E., Trask, J. & Glaser, R. (1991). Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. Psychosomatic Medicine, 53, 345-362.
- Kinnear, P.R. & Gray, C.D. (1994). SPSS For Windows Made Simple. Hove, U.K.: Lawrence Erlbaum Associates.
- Kirsch, I. (1997). Specifying non-specifics: Psychological mechanisms of placebo effects. In A. Harrington (Ed.), The Placebo Effect: An Interdisciplinary Exploration, pp. 166-186. Cambridge, MA: Harvard University Press.
- Knapp, M., Wilkinson, D. & Wigglesworth, R. (1998). The economic consequences of Alzheimer's Disease in the context of new drug developments. International Journal of Geriatric Psychiatry, 13, 531-543.
- Knight, B.G., Lutzky, S.M. & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: recommendations for future research. The Gerontologist, 33, 333-344
- Lawlor, B.A. (Ed). (1995). Behavioural Complications in Alzheimer's Disease: New Findings. American Psychiatric Association: Washington, DC.
- Lazarus, R.S. & Folkman, S. (1984). Stress, Appraisal and Coping. New York: Springer.

- Levin, E., Sinclair, I & Gorbach, P. (1984). The Supporters of Confused Elderly Persons at Home: Extract from the Main Report. London: National Institute of Social Work Research Unit.
- Livingston, G. (1990). The scale of the problem. In A. Burns & R. Levy (Eds), Dementia. London: Chapman & Hall Medical.
- LoGuidice, D., Waltrowicz, W. & McKenzie, S. (1995). Prevalence of dementia among patients referred to an aged care assessment team and associated stress in their carers. Australian Journal of Public Health, 19, 275-279.
- Magone, C.A., Sanguinetti, R.M., Buamann, P.D., Gonzalez, R.C., Pereyra, S., Bozzola, F.G., Gorelick, P.B. & Sica, R.E.P. (1993). Influence of feelings of burden on the caregiver's perception of the patient's functional status. Dementia, 4, 287-293.
- Magni, E., Zanetti, O., Buanchetti, A., Binetti, G. & Trabucchi, M. (1995). Evaluation of an Italian educational programme for dementia caregivers: Results of a small-scale pilot study. International Journal of Geriatric Psychiatry, 10, 569-573.
- McKee, K.J., Mutch, W.J., Ballinger, B., Philp, I., Gilhooly, M.L., Whittick, J. & Gordon, D.S. (1992). A comparison of the psychological characteristics of carers of elderly people with dementia and those without dementia. Paper presented at the British Psychological Society. Health Psychology Section, Annual Conference, St. Andrews, Scotland, 18 September.
- Melzer, D., Ely, M. & Brayne, C. (1997). Cognitive impairment in elderly people. Population based estimate of the future in England, Scotland and Wales. British Medical Journal, 315, 462.
- Melzer, D., Hopkins, S., Pencheon, D., Brayne, C. & Williams, R. (1994). Dementia. In A. Stevens and J. Rafferty (Eds.), Health Care Needs Assessment. Oxford: Radcliffe Medical Press.
- Montgomery, R.J.V., Gonyea, J.G. & Hooyman, N.R. (1985). Care-giving and the experience of subjective and objective burden. Family Relations, 34, 19-26.
- Morris, J. (1993). Dementia: Caring for the carers. Health Trends, 25, 3.

- Morris, R.G., Morris, L.W. & Britton, P.G. (1988a). Factors affecting the emotional wellbeing of the caregivers of dementia sufferers. British Journal of Psychiatry, 153, 147-156.
- Morris, R.G., Woods, R.T., Davies, K.S. & Morris, L.W. (1991). Gender differences in carers of dementia sufferers. British Journal of Psychiatry, 158 (Suppl. 10), 69-74.
- Morrissey, E., Becker, J. & Rubert, M.P. (1990). Coping resources and depression in the caregiving spouses of Alzheimer patients. British Journal of Medical Psychology, 63, 161-171.
- Mui, A.C. & Murrow-Howell, N. (1993). Sources of emotional strain among oldest caregivers: Differential experiences of siblings and spouses. Research on Ageing, 15, 50-69.
- Munro, J.K.M. (1995). Family caregivers of the medically ill elderly: Their stress and use of services. Unpublished dissertation, Master of Philosophy, University of Edinburgh.
- O'Connor, D.W., Pollit, P.A., Roth, C.P., Brook, C.P.B. & Reiss, B.B. (1990). Problems reported by relatives in a community study of dementia. British Journal of Psychiatry, 156, 835-841.
- OECD (1996). Caring for Frail Elderly People. Social Policy Studies, 19, OCED, Paris.
- Office of Population Censuses and Surveys Social Survey Division. (1989). General Household Survey 198 (Computer File, Colchester: ESRC Data Archive).
- Orne, M.T. (1969). Demand characteristics and the concept of quasi-controls. In R. Rosenthal & R.L. Rosnow (Eds), Artifact in Behavioural Research, pp. 143-179. New York: Academic Press.
- Ostbye, T. & Crosse, E. (1994). Net economic costs of dementia. Canadian Medical Association Journal, 151, 10.
- Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30, 583-594.
- Pfeiffer, E. (1979). A short psychiatric evaluation schedule. A new 15-item monotonic scale indicative of functional psychiatric disorder. In: Proceedings of

- the Bayer-Symposium, VII, Brain Function in Old Age. New York: Springer-Verlag.
- Poulshock, S.W. & Deimling, G.T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 29, 8-16.
- Pruchno, R. & Resch, N. (1989a). Husbands and wives as caregivers: Antecedents of depression and burden. Gerontologist, 29, 159-164.
- Rabins, P.V. (1984). Management of dementia in the family context. Psychosomatics, 25, 369-373.
- Rabins, P.V., Mace, H.L. & Lucas, M.J. (1982). The impact of dementia on the family. Journal of the American Medical Association, 248, 333-335.
- Raskind, M.A., Sadowsky, C.H., Sigmund, W.R., Beitler, P.J. & Auster, S.B. (1997). Effect of Tacrine on language, praxis, and noncognitive behavioural problems in Alzheimer's disease. Archives of Neurology, 54, 836-840.
- Reisberg, B., Schneider, L., Doody, R., Anand, R., Feldman, H., Haraguchi, H., Kumar, R., Lucca, U., mangone, C.A., Mohr, E., Morris, J.C., Rogers, S. & Sawasa, T. (1997). Clinical global measures of dementia. Position paper from the International Working Group on harmonization of Dementia Drug Guidelines. Alzheimer's Disease and Associated Disorders, 11 (Suppl. 3), 8-18.
- Reiss, M.F., Gold, D.P. , Gauthier, S. et al. (1994). Personality traits as determinants of burden and health complaints in caregiving. International Journal of Aging and Human Development, 39, 257-271.
- Rice, D., Fox, P.J., Max, W. et al. (1993). The economic burden of Alzheimer's disease care. Health Affairs, 12, 164-176.
- Robson, C. (1983). Experiment, Design and Statistics in Psychology: An Introduction (2<sup>nd</sup> Ed.). Harmondsworth, U.K.: Penguin Books
- Rocca, W.A., Hofman, A., Brayne, C. et al. (1991). Frequency and distribution of Alzheimer's disease in Europe: A collaborative study of 1980-1990 prevalence findings. Annals of Neurology, 30, 381-390.
- Rogers, S.L., Farlow, M.R., Doody, R.S. and the Donepezil Study Group. (1998). A 24-week, double-blind, placebo-controlled trial of donepezil in patients with Alzheimer's disease. Neurology, 50, 136-145.



- Rogers, S.L., Friedhoff, L.T. and the Donepezil Study Group (1996). The efficacy and safety of donepezil in patients with Alzheimer's disease: results of a US multi-centre, randomised, double-blind, placebo-controlled trial. Dementia, 7, 293-303.
- Rosen, W.G., Mohs, R.C. & Davis, K.L. (1984). A new rating scale for Alzheimer's disease. American Journal of Psychiatry, 141, 1356-1364.
- Roth, M., Tym, E., Mountjoy, C.Q. et al. (1986). CAMDEX: A standardised instrument for the diagnosis of mental disorder in the elderly with special reference to the early detection of dementia. British Journal of Psychiatry, 149, 698-709.
- Ruddle, H. & O'Connor, J. (1993). Caring without Limits? Sufferers of Dementia/Alzheimer's disease. A study of their Carers. Policy Research Centre, Dublin.
- Saad, K., Hartman, J., Ballard, C., Kurian, M., Graham, C. & Wilcock, G. (1995). Coping by carers of dementia sufferers. Age and Ageing, 24, 495-498.
- Schneider, L.S. & Farlow, M.R. (1995). Predicting response to cholinesterase inhibitors in Alzheimer's disease: Possible approaches. CNS Drugs, 4, 114-124.
- Schneider, J., Kavanagh, S.M., Knapp, M.R.J., Beecham, J. & Netten, A. (1993). Elderly people with advanced cognitive impairment in England: Resource use and costs. Ageing Society, 13, 27-50.
- Shultz, R., O'Brien, A.T., Bookwala, J. & Fleissnes, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes. Gerontologist, 35, 771-791.
- Scotsman (1995). Careworn – Inside Story. Tuesday 6<sup>th</sup> June.
- Scott, J.P., Roberto, K.A. & Hutton, J.T. (1986). Families of Alzheimer's victims: Family support to the caregivers. Journal of the American Geriatrics Society, 34, 348-354.
- Spitzer, R.L., Endicott, J. & Robins, E. (1978). Research diagnostic criteria: Rational and reliability. Archives of General Psychiatry, 35, 73-82.
- Stull, D., Kosloski, K. & Kercher, K. (1994). Caregiver burden and generic well-being: Opposite sides of the same coin? The Gerontologist, 34, 88-94.

- Toner, H.L. (1987). Effectiveness of a written guide of carers of dementia sufferers. British Journal of Consulting and Social Psychology, 5, 24-26.
- Vaux, A., Phillips, J., Holly, L. et al. (1986). The Social Support Appraisals (SS-A) Scale: Studies of reliability and validity. American Journal of Community Psychology, 14, 195-219.
- Vitaliano, P.P., Russo, J., Young, H.M., Teri, L. & Maiuro, R.D. (1991a). Predictors of burden in spouse caregivers of individuals with Alzheimer's disease. Psychological Aging, 6, 392-402.
- Vitaliano, P.P., Young, H.M. & Russo, J. (1991b). Burden: A review of measures used among caregivers of individuals with dementia. Gerontologist, 31, 67-75.
- Weiler, P.G., Chiriboga, D.A. & Black, S.A. (1994). Comparison of mental status tests: Implications for Alzheimer's patients and their caregivers. Journal of Gerontology, 49, 544-551.
- Whittick, J.E. (1988). Dementia and mental handicap: Emotional distress in carers. British Journal of Clinical Psychology, 27, 167-172.
- Whittick, J.E. (1989). Dementia and mental handicap: Attitudes, emotional distress and caregiving. British Journal of Medical Psychology, 62, 181-189.
- Whittick, J.E. (1992). Carers of the dementing elderly: Coping techniques and expressed emotion. Unpublished PhD thesis, University of Glasgow.
- Willaimson, G.M. & Schulz, R. (1993). Coping with specific stressors in Alzheimer's disease caregiving. Gerontologist, 3, 747-755.
- Yamanishi, Y., Ogura, H., Kosasa, T., Araki, S., Sawa, Y. & Yamatsu, K. (1990). Inhibitory action of donepezil, a novel acetylcholinesterase inhibitor on cholinesterase. Comparison with other inhibitors. In T. Nagatsu, A. Fisher & Yoshida, M. (Eds), Basic, Clinical and Therapeutic Aspects of Alzheimer's and Parkinson's Diseases, pp. 409-413. New York: Plenum Press.
- Zanetti, O, Frisoni, G.B., Bianchetti, A., Tamanza, G., Cigoli, V. & Trabucchi, M. (1998). Depressive symptoms of Alzheimer caregivers are mainly due to personal rather than patient factors. International Journal of Geriatric Psychiatry, 13, 358-367.

- Zarit, S.H. (1992). Conceptual and Methodological Issues in Caregiving Research. Proceedings of the International Conference on Family Caregiving Research, June 21-22th, 1990, Toronto.
- Zarit, S.H., Reever, K. & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20, 649-655.
- Zarit, S.H., Orr, N.K. & Zarit, J.M. (1985). The Hidden Victims of Alzheimer's Disease: Families under Stress. New York University Press: New York.
- Zarit, S.H., Todd, P.A. & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. Gerontologist, 26, 260-266.

## **APPENDIX A:**

### **INFORMATION SHEET**

You are invited to take part in a study which is being carried out to examine the different aspects of stress experienced by cohabiting relations of people with Alzheimer's disease who identify themselves as the primary caregiver.

It is now well recognised that caring for a relative with dementia can be a stressful experience. The study is interested in comparing the levels of stress experienced by cohabiting caregivers of people with dementia in different situations.

Your involvement in this study would be entirely voluntary and your relative's treatment would not be in any way affected if you chose not to take part.

Taking part in the study involves two interviews, 8-12 weeks apart with the researcher, Dr Jennifer Cleland, who is a Clinical Psychologist in Training. Each interview would last for about 1 – 1 1/2 hours.

In each interview, firstly, you would be asked some general questions about yourself and your caring role. You would then be asked to complete several questionnaires concerning the effects of caring for a relative and your own well-being. You are, of course, under no obligation to answer all the questions. All your answers will be kept in strictest confidence.

It is the normal course of action to inform your General Practitioner that you are participating in the study but this information can be withheld if you do not want your doctor to know about your involvement.

Dr Jennifer Cleland will contact you by telephone or letter to find out whether or not you are willing to participate in this study and, if so, to arrange a convenient time for you to meet with her either at Cornhill Hospital, Aberdeen, Whyteman's Brae Hospital, Kirkcaldy or your own home.

If you have any questions about this study, please do not hesitate to contact Dr Cleland at the Psychology Department, Cornhill Hospital (telephone 01224 663131 Ext: 57532) OR Stratheden Hospital, Cupar, Fife (tel.: 01334 652611 Ext.: 336)

Thank you.

**APPENDIX B:**  
**CONSENT FORM**

**Consent by patient/volunteer to participate in:** The influence of Aricept on stress and depression in caregivers of relatives with Alzheimer's disease.

Name of patient/volunteer:.....  
Principal Investigator:...Dr Jennifer Cleland, Department of Clinical Psychology, Royal Cornhill Hospital, Aberdeen and Stratheden Hospital, Cupar, Fife.

I have read the patient/volunteer information sheet on the above study and have opportunity to discuss the details with Dr Jennifer Cleland and ask questions. I fully understand what is proposed to be done.

I understand that I am under no obligation to take part in this study and that a decision not to participate would not alter the treatment that my relative would normally receive. I understand that I have the right to withdraw from this project at any stage and that to do so would not affect my relative's care in any way. I understand that this is non-therapeutic research from which I may not receive any obvious benefit.

I understand that this study has been approved by the Grampian Research Ethics Committee of Grampian Health Board and the University of Aberdeen has approved this study and may wish to inspect data collected at any time as part of its monitoring activities. I also understand that, where appropriate, my General Practitioner will be informed that I have taken part in this study.

I hereby fully and freely consent to participate in the study which has been fully explained to me.

Signature of patient/volunteer:.....  
Date:.....

I confirm that I have explained the nature and purpose of this study to the patient/volunteer named above.

Signature of Investigator:.....  
Date:.....



**APPENDIX C:**  
**SEMI-STRUCTURED INTERVIEW SCHEDULE**

Firstly, you will be asked some general questions about yourself and details about your caring role. You will then be asked to complete questionnaires concerning the effects of caring for a relative.

All your answers will be kept in strictest confidence.

1. What is your relationship to the patient (e.g., husband/wife/daughter/son)?
2. What is your age?
3. What age is the relative you care for?
4. Are you in paid employment?  
Yes ☐ No ☐
5. Do you have school-age children?  
Yes ☐ No ☐

**Formal Supports**

1. In addition to his/her GP, does your relative receive input from the following services?

Psychiatry	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Community Nursing	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Social Work	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Psychology	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Day Hospital	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Respite Care	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Home Carer	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Other	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

2. Are you in contact with a Carer's Support Group?

Yes

No

### **Family Supports**

1. How much do your family help with caring for your relative?

Not at all

A little

Sometimes

Quite a lot

Considerably

2. Would you like more assistance in caring for your spouse from:

a) Family

Yes

No

b) Formal Services

Yes

No

If (b) Formal services which further assistance would you find beneficial?

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3. Are you able to visit family/friends as often as you would like?

Yes

No

4. Are you able to engage in hobbies outside the home as often as you would like?

Yes

No

### **PHYSICAL HEALTH**

1. How would you rate your overall physical health at the present time?

Excellent

Good

Fair

Poor

Very Poor

2. Has your physical health been affected by caring for your relative?

Yes

No

3. How many times have you visited your GP in the last 6 months?

None

1 or 2

3 or 4

more than 5

## HOURS OF CARE

Approximately how many hours daily do you dedicate to **supervising** your relative? .....

Approximately how many hours daily do you dedicate to **assisting** your relative (e.g. helping him/her dress or wash)? .....

## DURATION OF SYMPTOMS AND CARING

Approximately how long ago did you first notice memory problems or other symptoms of dementia in your relative? .....

How long ago did you first begin to provide practical assistance to your relative? .....

## RELATIONSHIP WITH YOUR RELATIVE

What was your relationship with your relative like before the onset of their illness?

Do you regard your relationship with your relative as deteriorating since the onset of his/her illness?

Not at all      A little      Moderately      Quite a lot      Considerably

## CARE GIVING

In relation to your care giving, how much do you:-

1. **Believe that you have learned to deal with a very difficult situation;**

Not at all      A little      Moderately      Quite a lot      Considerably

2. **Feel that all in all, you're a good care giver;**

Not at all      A little      Moderately      Quite a lot      Considerably

3. **How much do you feel competent about your care giving;**

Not at all      A little      Moderately      Quite a lot      Considerably

4. **How self-confident do you feel about your care giving;**

Not at all      A little      Moderately      Quite a lot      Considerably

**APPENDIX D:**  
**BEHAVIOUR AND MOOD BISTURBANCE SCALE**

How often does your relative exhibit the following behaviours?

**1. Does not take part in family conversations.**

Never          Rarely          Sometimes          Frequently          Daily or more

**2. Does not read newspapers, magazines, etc.**

Never          Rarely          Sometimes          Frequently          Daily or more

**3. Sits around doing nothing.**

Never          Rarely          Sometimes          Frequently          Daily or more

**4. Does not show an interest in news about family/friends.**

Never          Rarely          Sometimes          Frequently          Daily or more

**5. Does not start or maintain a sensible discussion.**

Never          Rarely          Sometimes          Frequently          Daily or more

**6. Does not respond sensibly when spoken to.**

Never          Rarely          Sometimes          Frequently          Daily or more

**7. Does not understand what is said to him/her.**

Never          Rarely          Sometimes          Frequently          Daily or more

**8. Does not watch and follow television.**

Never          Rarely          Sometimes          Frequently          Daily or more

**9. Does not keep him/herself busy doing useful things.**

Never          Rarely          Sometimes          Frequently          Daily or more

**10. Fails to recognise familiar people.**

Never          Rarely          Sometimes          Frequently          Daily or more

**11. Gets mixed up about where he/she is.**

Never	Rarely	Sometimes	Frequently	Daily or more
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**12. Mood changes for no apparent reason.**

Never	Rarely	Sometimes	Frequently	Daily or more
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**13. Becomes irritable and easily upset.**

Never	Rarely	Sometimes	Frequently	Daily or more
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**14. Goes on and on about certain things.**

Never	Rarely	Sometimes	Frequently	Daily or more
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**15. Accuses people of things.**

Never	Rarely	Sometimes	Frequently	Daily or more
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**16. Becomes angry and threatening.**

Never	Rarely	Sometimes	Frequently	Daily or more
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**17. Appears unhappy and depressed.**

Never	Rarely	Sometimes	Frequently	Daily or more
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**18. Talks all the time.**

Never	Rarely	Sometimes	Frequently	Daily or more
-------	--------	-----------	------------	---------------

**19. Cries for no obvious reason.**

Never	Rarely	Sometimes	Frequently	Daily or more
-------	--------	-----------	------------	---------------

**20. Looks frightened and anxious.**

Never	Rarely	Sometimes	Frequently	Daily or more
-------	--------	-----------	------------	---------------

**21. Gets up unusually early in the morning.**

Never	Rarely	Sometimes	Frequently	Daily or more
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**APPENDIX E:**  
**PROBLEM BEHAVIOUR CHECKLIST**

How often does your relative exhibit the following behaviours?

**1. Unable to dress without help.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**2. Demands attention.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**3. Needs help getting in and out of a chair.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**4. Uses bad language.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**5. Needs help getting in and out of bed.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**6. Interferes with personal social life.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**7. Cannot wash without help.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**8. Physically aggressive.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**9. Needs help at meal times.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**10. Vulgar habits.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**11. Soiling**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**12. Creates personality clashes.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**13. Forgets things that happened.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**14. Temper outbursts.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**15. Likely to fall.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**16. Rude to visitors.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**17. Cannot manage stairs.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**18. Not safe outside, alone.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**19. Cannot be left alone for 1 hour or more.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**20. Wanders at night.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**21. Careless about own appearance.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**22. Unable to walk outside, unaided.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**23. Cannot hold a sensible conversation.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**24. Noisy, shouts.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**25. Wets him/herself.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**26. No concern for personal hygiene.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**27. Unsteady of feet.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

**28. Asking continual questions.**

Never	Occasionally	Frequently	
If true, this is;	Not a problem	A small problem	A great problem

NAME: \_\_\_\_\_ DATE: \_\_\_\_\_

Circle one question in each block for how you have been feeling over the past week.

**BECK INVENTORY**

1.     0     I do not feel sad  
       1     I feel sad  
       2     I am sad all the time and I can't snap out of it  
       3     I am so sad or unhappy that I can't stand it
  
2.     0     I am not particularly discouraged about the future  
       1     I feel discouraged about the future  
       2     I feel I have nothing to look forward to  
       3     I feel that the future is hopeless and that things cannot improve
  
3.     0     I do not feel like a failure  
       1     I feel I have failed more than the average person  
       2     As I look back on my life, all I can see is a lot of failures  
       3     I feel I am a complete failure as a person
  
4.     0     I get as much satisfaction out of things as I used to  
       1     I don't enjoy things the way I used to  
       2     I don't get real satisfaction out of anything any more  
       3     I am dissatisfied or bored with everything
  
5.     0     I don't feel particularly guilty  
       1     I feel guilty a good part of the time  
       2     I feel quite guilty most of the time  
       3     I feel guilty all of the time
  
6.     0     I don't feel I am being punished  
       1     I feel I may be punished  
       2     I expect to be punished  
       3     I feel I am being punished
  
7.     0     I don't feel disappointed in myself  
       1     I am disappointed in myself  
       2     I am disgusted with myself  
       3     I hate myself
  
8.     0     I don't feel I am any worse than anybody else  
       1     I am critical of myself for my weakness or mistakes  
       2     I blame myself all the time for my faults  
       3     I blame myself for everything bad that happens
  
9.     0     I don't have any thoughts of killing myself  
       1     I have thoughts of killing myself, but I would not carry them out  
       2     I would like to kill myself  
       3     I would kill myself if I had the chance
  
10.    0     I don't cry any more than usual  
       1     I cry more now than I used to  
       2     I cry all the time now  
       3     I used to be able to cry, but now I can't cry even though I want to

11./



**APPENDIX F:**  
**BECK DEPRESSION INVENTORY**

**APPENDIX G:**  
**RELATIVES' STRESS SCALE**

Please circle the opinion, which you think is most applicable to your situation.

**1. Do you ever feel that you need a break?**

Never      Rarely      Sometimes      Frequently      Always

**2. Do you ever get depressed by the situation?**

Not at all      A little      Moderately      Quite a lot      Considerably

**3. Has your own health suffered at all?**

Not at all      A little      Moderately      Quite a lot      Considerably

**4. Do you worry about accidents happening to your relative?**

Never      Rarely      Sometimes      Frequently      Always

**5. Do you feel that there will be no end to the problem?**

Never      Rarely      Sometimes      Frequently      Always

**6. Do you find it difficult to get away on holiday?**

Never      Rarely      Sometimes      Frequently      Always

**7. How much has your social life been affected?**

Not at all      A little      Moderately      Quite a lot      Considerably

**8. How much has the household routine been upset?**

Not at all      A little      Moderately      Quite a lot      Considerably

**9. Is your sleep interrupted by your relative?**

Never      Rarely      Sometimes      Frequently      Always

**10. Has your standard of living been reduced?**

Not at all      A little      Moderately      Quite a lot      Considerably

**11. Do you feel embarrassed by your relative?**

Never      Rarely      Sometimes      Frequently      Always

**12. Are you at all prevented from having visitors?**

Never      Rarely      Sometimes      Frequently      Always

**13. Do you ever get cross and angry with your relative?**

Never      Rarely      Sometimes      Frequently      Always

**14. Do you sometimes feel frustrated at times with your relative?**

Never      Rarely      Sometimes      Frequently      Always

**15. Do you ever feel that you can no longer cope with the situation?**

Never      Rarely      Sometimes      Frequently      Always